6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

#PWSCARE24

EJF

IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO is committed to reducing the environmental impact of its conferences. This booklet is made available as a digital version only.

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Conference sponsors

The EJF (Evangelisches Jugend- und Fürsorgewerk) is a nationwide operating, Christian-oriented organisation in the social sector. It provides assistance for people of all age groups and beliefs who require special personal and social care. The EJF develops and operates both outpatient and inpatient services for people with disabilities, for children, youth, and families, for homeless and refugee individuals, as well as for seniors.

Since 2001, EJF in Berlin has been offering a syndrome-specific supervised living arrangement for individuals with Prader-Willi syndrome.

Conference Partner

Friends of IPWSO improves the lives of the global PWS community by funding IPWSO's family support, educational and scientific networking activities. Friends of IPWSO is a United States not-for-profit, committed to raising funds to help those who have Prader-Willi syndrome living throughout the world. Friends have generously provided funds to support travel fellowships for IPWSO's 2022 Conference. If you would like to make a difference and help Friends of IPWSO raise much needed funds, donate here.

Travel Scholarship Partner

Soleno Therapeutics is focused on the development and commercialisation of novel therapeutics for the treatment of rare diseases. The company's lead candidate, DCCR (Diazoxide Choline) Extended-Release tablets, a once-daily oral tablet, is being evaluated for the treatment of Prader-Willi syndrome.

We recently completed a Phase 3 development program to support a planned FDA new drug application. Our priority is to bring the first approved treatment to patients to manage the most burdensome aspects of this devastating disorder.

Gold Sponsor

Acadia is advancing breakthroughs in neuroscience to elevate life by bringing vital solutions to people who need them most. We developed and commercialised the first and only FDA-approved drug for the treatment of Rett syndrome and the first and only FDA-approved drug to treat hallucinations and delusions associated with Parkinson’s disease psychosis. Our clinical-stage development efforts are focused on Prader-Willi syndrome, Alzheimer’s disease psychosis and multiple other programs targeting neuropsychiatric symptoms in central nervous system disorders. Learn more at Acadia.com.

Silver Sponsor

Palo Biofarma is a leading clinical-stage biotech company dedicated to creating new medicines. Our focus on adenosine signaling drives our innovation. With 6 new drug candidates in different testing phases, notably PBF-999 for Prader-Willi syndrome, we're committed to pioneering advancements in medicine. Our mission is grounded in scientific excellence, aimed at reshaping patient care and well-being, alleviating human suffering through cutting-edge advancements.

Silver Sponsor

Prader-Willi Stichting is the patient organization in the Netherlands representing the interests of persons with Prader-Willi syndrome and the people in their immediate environment such as parents, relatives and caregivers. The PWS-community in the Netherlands is relatively small, but large enough to lobby governments, health insurance companies, researchers, hospitals, health care providers and other social organisations through education and information, peer contact, advocacy and international cooperation. We support this conference in Berlin because it’s very important to exchange PWS expertise.

Silver Sponsor

Conference Sponsors

Aardvark Therapeutics is dedicated to bringing novel drugs that activate innate homeostatic pathways to patients living with neurodevelopmental, metabolic and inflammatory disorders.

The lead product, ARD-101, is a first-in-class oral drug that is restricted to the gut which contributes to its safety, yet conveys systemic effects by stimulating gut peptide hormone secretion and gut-brain signaling with broad therapeutic potential. A phase 2 clinical trial in Prader-Willi syndrome documented excellent safety and hunger control, supporting continued development.

Bronze Sponsor

AME Community Services, Inc. is a family-owned, person-centered company that was founded in 1992 with a commitment to supporting individuals with disabilities to achieve their goals, big or small. AME supports adults and children with Prader-Willi syndrome and currently serves 38 individuals with PWS in 11 Community Residential Settings. We tailor our services based on individual preferences for how people want or need to be supported to live their best life. AME is located in Minnesota, USA.

Bronze Sponsor

Resilience is a fully Irish owned Health and Social Care provider founded in 2011 in Ennis, Co. Clare, Ireland. The company's main purpose is to help improve the quality of lives of people with intellectual and physical disabilities. It empowers them to build resilience in overcoming everyday challenges and adversities they have.

Resilience provides services across most of Ireland under two divisions:

- Advanced Community Care: We provide nurses into the home for people (mainly children) who need at home hospital care 24 hours.

- Disability Services (Social Care): We provide Residential Care (20 houses), Day Services and Outreach for young adults and older adults with Intellectual Disabilities and Autism.

Bronze Sponsor

Conference Sponsors

Located on Cape Cod, Massachusetts, USA, Latham Centers is a leader in special education and therapeutic services for children and adults with disabilities. We are internationally renowned for our success in working with individuals with Prader-Willi syndrome. Our mission is to create opportunities for independence, self-worth, and happiness for individuals with complex special needs.

Bronze Sponsor

The Prader-Willi-Syndrom Vereinigung Deutschland e.V. (PWSVD) is an association of individuals with PWS (Prader-Willi syndrome) and their families, with over 750 members nationwide. Founded in November 1991, our mission is to raise awareness in the public and promote understanding of PWS and its treatment options. We provide support to those seeking guidance in all aspects of life and sponsor projects to enhance therapy measures. Additionally, we organize workshops and recreational activities for individuals with Prader-Willi syndrome.

Star Sponsor

Welcome
from our conference partner

As the CEO of EJF gemeinnützige AG and a proud partner of the International Prader-Willi Syndrome Organisation (IPWSO), I warmly welcome all of you to the 6th International Conference for Prader-Willi syndrome Caregivers in the vibrant city of Berlin and the equally picturesque district of Berlin-Köpenick.

I am delighted that EJF gemeinnützige AG could play a significant role in ensuring that this conference could swiftly relocate to Berlin due to the conflict outbreak in Israel. Our collaboration with IPWSO, along with your unwavering support through your presence, underscores the importance of partnerships in addressing global health challenges.

Our shared journey began over a decade ago, inspired by the pioneering spirit of Pam Eisen and the initial Caregivers' Conferences in Herne in 2008 and 2009. Since then, thanks to the tireless dedication of professional providers, caregivers, and the IPWSO's PPC Board, we have witnessed remarkable progress in Prader-Willi syndrome care worldwide.

Dr. Andreas Eckhoff,
Chairman of the Board,
EJF gemeinnützige AG

This conference stands as a testament to our collective commitment to enhancing the lives of individuals with Prader-Willi syndrome. As we gather in Berlin from May 21st to 23rd, 2024, we embark on three days of shared learning, exchange, and growth. During this time, we will delve into crucial topics that shape our caregiving practices:

Research: Unveiling the latest scientific findings and breakthroughs.

The Future of PWS Support: Anticipating the evolving landscape of care.

Relationships: Nurturing connections within our global community.

Technology: Leveraging innovations for better outcomes.

Balancing Rights and Responsibilities in Care: A delicate equilibrium.

Behaviour Management: Diagnostic tools and effective strategies.

Role of Therapies: Empowering those under our care.

Autonomy and Ageing: Addressing unique challenges.

Our collective wisdom, shared experiences, and diverse perspectives will shape the future of Prader-Willi syndrome care. Let us wholeheartedly engage, learn from one another, and forge lasting bonds. Together, we can create a world where individuals with PWS thrive and each individual has a high quality of life and successful social participation, supported by compassionate and informed caregivers.

I extend heartfelt gratitude to the sponsors, whose generosity has made this conference possible. To those joining for the first time, a warm welcome! And to all returning participants, thank you for your continued dedication.

Looking forward to seeing everyone in Berlin!

Welcome from IPWSO's PPC Board

Lynn Garrick

Lynn Garrick,
Chair, IPWSO Professional Providers and Caregivers Board

It is with great pleasure that we welcome our caregiver delegates, colleagues, and friends to the 6th International Prader-Willi Syndrome Caregivers' Conference in Berlin, Germany. We're delighted to be joined by people from across the globe. Thank you all for your attendance and participation - we hope you find this experience enriching, informative and enjoyable.

This event is in keeping with the spirit of the first Caregivers' Conference organised by Pam Eisen in Herne, in 2008. The Pam Eisen Lecture, which we'll hear on Day 1 of the conference, has since become a highlight of the programme, allowing us all time to reflect on how far we have come as a PWS community, and how much we can continue to accomplish together.

Professional providers and caregivers are integral to the health and well-being of those living with Prader-Willi syndrome (PWS). It remains critical that caregivers have access to the latest information and can learn in a collaborative setting about topics essential to care provision.

As you immerse yourself in the programme, we hope you'll agree this is **a conference by PWS caregivers, for PWS caregivers**. The Professional Providers and Caregivers Board (PPCB) of IPWSO have developed a packed 3-day agenda based on the issues that caregivers tell us are important to them. In August 2023 we sent out a survey which asked what topics you would like to hear about as part of the conference. We had previously asked the same question to participants of the PPC Conference (IPWSO 2022) in Ireland.

You told us topics such as research, the future of PWS support, relationships, technology, balancing individual rights with the duty of care, diagnostic instruments in behaviour management, the role of therapies, autonomy, aging and more were at the forefront of mind when you think of what is important in your work. While we know there will never be enough time to fully disentangle all the complexities of PWS, we hope you agree that the programme promises a terrific forum to collectively address some of the big issues in depth.

You are not just here to listen – please think of this as a collaborative environment where professional caregivers worldwide can exchange practice-driven knowledge and actively contribute their own experiences to enhance the care they provide and develop new methods of support in an ever-changing world.

Our heartfelt thanks go to everyone who is presenting, running a workshop, and participating in discussions over the conference and also to all those who are displaying their research findings, which always provide a richer depth of knowledge and spark great discussion. Thank you also to the members of the PPCB, who have worked very hard to plan and deliver this conference.

Finally, a big thank you to our conference partner, EJF, and to our sponsors and exhibitors; your support greatly enhances the conference and indeed, without it, this vital opportunity to renew and sustain our efforts to increase our understanding and provide the necessary supports for people living with syndrome, could not happen. We wish you all an enjoyable and memorable conference.

Caregiver delegates meeting

Wednesday 22 May 5-6pm

Conference room 5

Neil Gumley
PPCB Member,
Caregiver Delegate Liaison

Caregiver Delegates are the point of contact that IPWSO's Professional Providers and Caregivers Board uses to distribute information about residential support.

At each caregivers' conference, we take some time to meet with our Caregiver Delegates to review future planning and how we can best work with you as a group in the years to come.

All are welcome

Caregiver Delegates are appointed by their country's PWS Association, but we know that many more of you are ready to support our growing PWS caregiver community. Please join us, whether you're an offical Caregiver Delegate, or someone who wishes to become more involved with this important work. We look forward to meeting with you.

Conference dinner

Wednesday 22 May, from 7pm

Conference rooms 1-2

You're invited!

IPWSO and EJF are delighted to welcome all of our delegates to the conference dinner on the 2nd day of the conference. This is included as part of your registration.

Please join us for a wonderful evening of good food, great conversation, music and merrymaking! We look forward to sharing this time with you.

Caregivers on camera

Throughout the event we'll be asking delegates to participate in short video interviews. We want some of the learning from the conference to be accessible to people who aren't able to attend in person. We invite everyone attending to join in, and share your knowledge and experience with the caregiver community worldwide.

Positive about PWS

What positive qualities or skills do people with PWS you know have?

How do you overcome stereotypes?

Research

How can research bring benefits to people with PWS?

What should research focus on?

Your advice

What is one piece of advice you would give someone who is just learning about PWS?

Our thanks go to Friends of IPWSO (USA) for supporting written and filmed educational resources at the conference that will be made freely available to professional caregivers and others from around the world.

About IPWSO

IPWSO was established in 1991. Since then, we have supported and connected national PWS associations, as well as people with PWS, their families and the professionals who work with them.

Forty-six national PWS associations make up our current membership and we support individuals in over seventy other countries. While we are proud of our heritage and recognise that some people with PWS now achieve far better outcomes than were believed possible in the past, we are acutely aware that people with PWS and their families continue to face serious challenges, particularly in countries where knowledge is limited and treatments, services and support are difficult to access.

We believe that timely and consistent access to reliable information, as well as early diagnosis, informed medical care and therapeutic services, and access to social care and support are all necessary to enable people with PWS and their families to achieve the best possible outcomes.

In some countries, early diagnosis and good health have become common and a generation of adults with PWS is emerging for whom new models of care and support may be needed. In other countries, early diagnosis remains rare and life-threatening levels of obesity are routinely observed.

We operate in a challenging environment. However, we are committed to working for a world where all people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

Support us

Your donation is instrumental in ensuring that families of people with PWS and professionals who support people with PWS worldwide can access the information and support they need, when they need it.

With generous support from our donors and Friends of IPWSO (USA), IPWSO are delighted to offer travel scholarships to worthy professionals to enable their attendance at events and conferences around the world.

If you are able to, please consider donating so that we can help more people access the information, support and guidance they need.

To make a donation, please scan the QR code above, or online visit www.ipwso.org/make-a-donation

For donors based in the US, please donate through Friends of IPWSO.

Thank you for your compassion and generosity. Together, we can make a profound difference.

United in HOPE

2025 PWS CONFERENCE

2025 INTERNATIONAL PWS CONFERENCE | PHOENIX, AZ

Something for everyone!

- Clinical & Scientific Program
- Professional Providers Program
- Family Program
- Camps for Youths & Adults with PWS

June 24-28, 2025

Arizona Grand Resort & Spa

www.ipwso.org/conference-2025

Registration available June 1, 2024

Prader-Willi SYNDROME ASSOCIATION | USA
SAVING AND TRANSFORMING LIVES

IPWSO
International Prader-Willi Syndrome Organisation

FOUNDATION FOR PRADER-WILLI RESEARCH

Organising committee

The Professional Providers and Caregivers Board (PPCB) of IPWSO brings best practice, information, knowledge and techniques to those providing care to the global PWS community, in order that those living with PWS may live their lives to the highest quality.

Lynn Garrick	Chair
Laura Keane	Co-Chair
Patrice Carroll	
Shelly Cordner	IPWSO Project Manager
Larry Genstil	
Neil Gumley	
Norbert Hödebeck-Stuntebeck	
Hubert Soyer	
Mary K. Ziccardi	

Day 1: Tuesday 21 May 2024

09:00-09:30	**Opening and welcome** **Room: Conference 1+2** Dr Andreas Eckhoff, CEO of EJF gemeinnützige AG, Germany Tony Holland, IPWSO President, University of Cambridge, UK Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board (PPCB), USA, and Hubert Soyer, PPCB Member, Germany
09:30-09:45	Video: **Thank you, caregivers!** People with PWS from around the world
09:45-10:15	Pam Eisen Lecture: **The future of care for people with PWS** Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany
10:15-10:45	Break
10:45-11:15	**IPWSO's initiative to give people with PWS a voice** Svetlana Labun, Managing Director, EJF Hollerhaus gGmbH, Trustee, IPWSO, Germany **People with PWS give themselves a voice: Requirements and solutions (example of a group in Germany)** Christian Blohm, Metalworker, Germany
11:15-11:30	**Outcomes for persons with Prader-Willi syndrome in full-time services: Findings from international archival data and future research directions** Brian Hughes, Professor of Psychology, University of Galway, Ireland
11:30-11:45	**Operationalised list of infrastructure and staff skills required for specialised care of PWS as rated by residential care providers in the USA** Janice Forster, MD, Board Certified General and Child and Adolescent Psychiatrist in private practice in Pittsburgh PA, USA
11:45-12:00	**Service involvement for children seen in the specialist PWS child mental health service in UK: Supporting a multi-agency approach to food security and wellbeing (and how restrictions can be liberating)** Dr Sarah Carman, National and Specialist CAMHS Specialist Prader Willi Syndrome Service, Mental Health of Intellectual Disabilities Team, SCAAND, Michael Rutter Centre, South London and Maudsley NHS Foundation Trust, UK

Day 1: continued

12:00-12:15	**Introduction to the poster presentations and afternoon workshops** Laura Keane, Co- Chair of the IPWSO Professional Providers and Caregivers Board, Chief Executive, Resilience Healthcare, Ireland			
12:15-13:15	Lunch break			
13:15-13:45	**Poster presentations** **Room: Conference hall** **Moderated by:** Laura Keane, Chief Executive, Resilience Healthcare, Ireland			
13:45-15:30	Workshop: **Art as a therapeutic approach for people with PWS** **Room: Conference 4** Led by: Tovi Florsheim	Workshop: **Balancing rights and restrictions for individuals with PWS** **Room: Conference 1** Led by: Hubert Soyer, Gary Brennan, Lynn Garrick	Workshop: **Friends, partnerships and sexuality** **Room: Conference 2** Led by: Patrice Carroll, Neil Gumley	Workshop: **Understanding behaviour** **Room: Conference 5** Led by: Norbert Hödebeck-Stuntebeck, Tony Holland
15:30-16:00	Break			
16:00-17:45	**Therapy options: Art (continued)**	**Balancing rights and restrictions (continued)**	**Friends, partnerships and sexuality (continued)**	**Understanding behaviour (continued)**
17:45	End of day			

Day 2: Wednesday 22 May 2024

09:00-10:30	**Therapy options: ABA (continued)** Led by: Vikacha Phiri	**Balancing rights and restrictions (continued)**	**Friends, partnerships and sexuality (continued)**	**Understanding behaviour (continued)**
10:30-11:00	Break			
11:00-11:30	**Overview of the Clinical Trials Process** **Room: Conference 1+2** Nathalie Kayadjanian, Ph.D. Scientific advisor, Raymond A. Wood Foundation, Trustee, IPWSO, USA			
11:30-12:30	**Research and Clinical Trials Updates** Santiago Figueroa Pérez, COO, Palobiofarma, Spain June Sanson, Executive Director of Patient Advocacy & Industry Relations, Acadia Pharmaceuticals, USA Dr. Dairine Dempsey, VP, Europe, Soleno Therapeutics Inc., Ireland **Moderated by:** Tony Holland, IPWSO President, University of Cambridge, UK			
12:30-13:30	Lunch break			
13:30-15:15	Workshop: **Ageing** **Room: Conference 4** Led by: Susanne Blichfeldt, Larry Genstil	Workshop: **Staff retention: and what happens when there is a breakdown?** **Room: Conference 1** Led by: Lynn Garrick, Claire Poor-Harmon	Workshop: **Friends, partnerships and sexuality (repeated)** **Room: Conference 2** Led by: Patrice Carroll, Neil Gumley	Workshop: **Understanding behaviour (repeated)** **Room: Conference 5** Led by: Norbert Hödebeck-Stuntebeck, Tony Holland
15:15-15:45	Break			
15:45-17:00	**Aging (continued)**	**Staff retention (continued)**	**Friends, partnerships and sexuality (continued)**	**Understanding behaviour (continued)**
17:00-19:00	Break			
19:00-23:00	**Conference dinner** **Room: Conference 1+2**			

Day 3: Thursday 23 May 2024

09:00-10:30	**Ageing (continued)**	**Staff retention (continued)**	**Friends, partnerships and sexuality (continued)**	**Understanding behaviour (continued)**
10:30-11:00	Break			
11:00-11:30	**Meaningful employment for people with PWS** Larry Genstil, Psychologist, Israel			**Room: Conference 1+2**
11:30-11:45	**Network Switzerland** Bastian Bühler, Social educator/Team leader, Stiftung Arkadis, Switzerland			
11:45-12:00	**PWS Competence Center Austria** Janine Sinner, Team Leader, Caritas Upper Austria, Austria			
12:00-13:30	Lunch break			
13:30-14:15	Panel discussion: **Self-determination, self-control: Opportunities and limitations** Lee Chamberlain, VP & Chief Strategy Officer, Latham Centers, Inc., USA Maria Kirby, Head of Clinical Services, Resilience Healthcare, Ireland Fred Nikolai, Chairman Prader-Willi Stichting, The Netherlands Michelle Torbert, President, Friends of IPWSO (USA), USA **Moderated by:** Hubert Soyer, Psychologist, Germany			
14:15-15:00	Questions and Answers: **Your medical questions** David M. Agarwal, MD, FSIR, Indiana University School of Medicine, USA Susanne Blichfeldt, MD, The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark Janice Forster, MD, Developmental Neuropsychiatrist, Pittsburg Partnership, Pittsburgh, PA, USA **Moderated by:** Lynn Garrick, Programme Director, AME Community Services, USA			

Day 3: continued

15:00-15:45	Panel discussion: **What supports are available for people with PWS who overburden the system with their challenging behaviour? Models and limits** Patrice Carroll, Director of PWS Services, Latham Centers, USA Lynn Garrick, Programme Director, AME Community Services, USA Larry Genstil, Psychologist, Israel Myles Kelly, Project Manager, PWSA UK, UK **Moderated by:** Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany
15:45-16:15	**Close and thank you** Lynn Garrick, Chair of the IPWSO Professional Providers and Caregivers Board, and Laura Keane, Co- Chair

**Please note: The Conference Organisers reserve the right to amend the content and timings of the programme, if deemed necessary.*

Speakers

David M. Agarwal, MD, FSIR

Indiana University School of Medicine, USA

Dr. David Agarwal is a Vascular and Interventional Radiologist board certified in both Diagnostic Radiology and Interventional Radiology, former Director of the Indiana University School of Medicine Vascular & Interventional Radiology Fellowship training program, and currently an Associate Professor of Clinical Radiology & Imaging Sciences specializing in the treatment of liver cancer and solid organ transplant intervention in the IU Health and Eskenazi systems in Indianapolis. David is a member of the Prader-Willi Syndrome Association USA Clinical/Scientific Advisory Board (CSAB) and a former member of the PWSA|USA Board of Directors. With his wife Janice, a NeuroDevelopmentally trained Pediatric Physical Therapist, David founded Watch Us Farm, a private local nonprofit organisation and Medicaid waiver service provider employing and training adults with intellectual disabilities in community integrated settings. Although not directly involved in primary care medicine, David has 24 years of high-level common-sense experience dealing with day-to-day medical issues involving Prader-Willi syndrome.

Susanne Blichfeldt, MD

The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark
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Pediatrician (pediatric neurology, general and developmental pediatrics) Susanne has many years' experience of diagnoses, clinical treatment, education and advising families and professionals about PWS in Denmark and abroad. She has undertaken research about growth hormone treatment in PWS and has published widely. Susanne is co- founder of the PWS Danish Association (1986), and leader of the Advisory Board in the Association. She has been involved with IPWSO since 1991 and has been a member of the IPWSO Clinical and Scientific Advisory Board since 2004 and is a member of the IPWSO Famcare Board. She is a former member of the IPWSO Trustee Board and the Professional Providers and Caregivers Board. Susanne is married with children and grandchildren and has a son, 45 years-old, living with PWS.

Christian Blohm

Metalworker, Germany

Christian Blohm finished school in 1995 and between 1996 and 1998 studied to become a metal worker, graduating from a vocational training center in Bad Oeynhausen, Germany.

Since 1998 he has worked full-time in various departments in the metal and packaging area of a workshop for people with disabilities. Christian also works as a trained reader for "Easy Language" in Germany.

Since 1998, Christian has been living in various group homes for people with Prader-Willi syndrome. He has served as a home advisory board representative on various committees for several years, and is currently a member of the advisory board for people with disabilities of the city of Lübbecke, Germany.

Gary Brennan

National Development Manager, PWSAI, Ireland
gary.brennan@pwsai.ie

Gary Brennan is National Development Manager for the Prader-Willi Syndrome Association in Ireland. He joined PWSAI in May 2019.

Gary has 16-years' experience in the social care disability sector, 10 of which were in residential care supporting adults with PWS. Gary holds an Honours degree in Social Care from the Technological University of Dublin, a Diploma in Training and Further Education from the National University of Ireland, Galway and a Certificate in Leadership and Management from the University of Limerick.

Gary has recently co-authored a report on service provision for people with PWS in Ireland with a strong focus on the voice and lived experience of people with PWS and their families. He is a huge supporter of self-advocacy for adults with PWS and co-chairs the PWS Adult Stepping Up Advocacy Support Group that links the voice of people with PWS to the strategies of the association with a view to develop a strong foundation within PWSAI from which the future of PWS awareness, support and services provision can advance.

Bastian Bühler

Social Educator/Team Leader, Stiftung Arkadis, Switzerland
bastian.buehler@arkadis.ch

Bastian Bühler originally trained as an electronics technician, and made a significant career shift after completing his apprenticeship. He felt compelled to explore the field of social work further and thus pursued higher education in this domain. In 2013, Bastian earned a Bachelor of Arts degree in Social Work. Throughout and following his studies he worked for the Arkadis Foundation, gaining valuable experience in the social services sector.

Since 2018, Bastian has worked as a team leader in the residential group for people with Prader-Willi syndrome. Starting from next July, he will be taking on the position as department head for individual living. Another notable achievement in his career within the Prader-Willi syndrome field was his election to the board of the Prader-Willi Syndrome Association Switzerland. Additionally, Bastian proudly serves as the Caregiver Delegate for Switzerland, advocating for the needs and rights of individuals with Prader-Willi syndrome and their families.

Sarah Carman

Dr Sarah Carman, Principal Clinical Psychologist, Service for Complex Autism and Associated Neurodevelopmental Disorders (SCAAND), South London and Maudsley NHS Trust, UK
Sarah.Carman@slam.nhs.uk

Dr Sarah Carman is Principal Clinical Psychologist in the Mental Health of Intellectual Disability team, which includes the national Prader-Willi syndrome service for children and young people. The team is part of the Service for Complex Autism and Associated Neurodevelopmental Disorders (SCAAND), a National and Specialist CAMHS team based in London, in the South London and Maudsley NHS Trust.

Dr Carman specialises in supporting the complex mental health needs of children with intellectual disability and/or autism, and working with young people, families and multi-agency professionals to address behaviour that challenges. She contributes clinically to the multidisciplinary work of the PWS service, providing assessment, intervention and consultation for children and young people, their families and professional networks. She works closely with Natasa Momcilovic, Clinical Behaviour Therapist and lead, to support the clinical leadership, service development and ongoing evaluation work of the PWS service.

Dr Carman teaches on postgraduate and professional development trainings across London and the south of England through the IoPPN, King's College London and the University of Exeter. From 2022-2023, she also held the role of Safeguarding Children lead for National and Specialist Outpatient CAMHS, providing consultation and training to clinicians from more than twenty specialist services.

Patrice Carroll

Director of PWS Services, Latham Centers, USA
pcarroll@lathamcenters.org

Patrice Carroll is the director of PWS services for both children and adults at Latham Centers in Massachusetts, USA. Patrice received her MSW from Simmons College, Boston, MA 2008. Patrice is the co-chair of the PWSA | USA professional providers advisory board and has been working with children and adults diagnosed with PWS since 2002. Patrice is a co-author of the book “Living Healthy with Prader-Willi Syndrome”. In addition to her experience with developing person-centered vocational programming for people with PWS, she has specialised in the management of skin and rectal picking using intensive, non-contingent, sensory stimulation.

Lee Chamberlain

Vice-President, Operations, Latham Centers, USA
lchamberlain@lathamcenters.org

Background: CSO/COO/Vice President/Sr. Program Operations Manager with 20 years' experience providing staff, program & operational leadership across public and private organisations. Expertise including program, staff, operations and fiscal management maximizing efficiency and improving service delivery, Outstanding knowledge of human resource development, high performance team building, and strong financial management and stakeholder relations. Data driven and results oriented, effective problem solving with consistent success in maximising operations and achieving organisation's goals.

Dr Dairine Dempsey

VP, Europe, Soleno Therapeutics Inc., Ireland
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VP, Europe for Soleno Therapeutics, Dairine has almost 25 years of experience in the pharmaceutical, biologic and device industries, including 9 years in the Irish Health Products Regulatory Authority working with the European Medicines Agency and the European Commission on technical issues and policy development. She has been involved in the successful global clinical development and post-marketing management of over 10 pharmaceutical products across multiple therapeutic areas, many for rare diseases.

Dr Andreas Eckhoff

CEO of EJF gemeinnützige AG, Germany

Dr. Andreas Eckhoff holds a Ph.D. in Business Administration and is a Graduate industrial engineer from the Technical University Berlin and the University of California, Los Angeles. He serves as the Chief Executive Officer of EJF non-profit AG (formerly EJF-Lazarus gAG) since March 2008. Prior to this role, he held the position of Chief Financial Officer at Daimler-Chrysler Services Mobility Management GmbH from 1997 to 2007. Dr. Eckhoff has also held various roles within Daimler-Chrysler AG in Stuttgart and Berlin.

Since January 2016, he has been the Chairman of the Board at EJF non-profit AG. Simultaneously, he serves as the Managing Director of EJF e.V., EJF Service und Fürsorge gGmbH, EJF Diakonie-Pflege gGmbH, also of EJF Hollerhaus gGmbH and EJF Gastro- und Hotelbetriebs GmbH.

Dr. Eckhoff is a strong advocate for respectful assistance on equal terms and emphasises the importance of diversity for success.

Tovi Florsheim

MA, Art Therapist, BA in Special Education, Israel
tovigen@gmail.com

Tovi Florsheim is a certified art therapist from Israel. She has a BA in Special Education and an MA in Art Therapy. Tovi has been working in a Prader-Willi group home for 18 years in different roles – as caregiver, management positions, art teacher, and for the past 5 years as an art therapist. Through all her degrees, she studied and researched PWS issues and has presented about integrating students with PWS in regular education at the IPWSO conference in Toronto in 2016. In her training period as an art therapist, Tovi treated people with PWS, alongside other special needs populations: intellectual disability, autism, CP, FXS, OCD, ADD, ADHD and more. Today in addition to her work in the PWS group home, she also works as an art therapist in a special education school.

Janice Forster, MD

Developmental Neuropsychiatrist,
Pittsburg Partnership, Pittsburgh, PA, USA
janiceforstermd@aol.com

Janice L Forster, MD is a Board Certified General and Child and Adolescent Psychiatrist in private practice in Pittsburgh PA, where she specialises in Developmental Neuropsychiatry, a subspecialty devoted to the evaluation and treatment of individuals with neurodevelopmental disorders. For over 30 years, she has acquired special expertise in the management of children, adolescents, and adults with PWS across all levels of care. She is a clinical consultant to the Prader-Willi Syndrome Association of USA (PWSA-USA) where she serves on the Clinical Advisory Board. She is also a member of the IPWSO Clinical and Scientific Board, a founding member of IPWSO's Professional Provider Caregiver Board, and a co-founder of the Pittsburgh Partnership, specialising in clinical assessment, program consultation, and psychoeducational interventions for parents, professionals, and providers working with PWS. Dr Forster edited the CD book Best Practice Guidelines for Standard of Care for Residential Living in PWS (2010), and she has written chapters on the Psychiatric Phenotype in PWS and Pharmacotherapy in PWS in the new edition of the PWS Management Book (2022).

Johannes Fuhrmann

Personal testimonial on Rights and Restrictions for people with PWS, Germany

I am Johannes Fuhrmann, born in 1996 in Mannheim, Germany. My life has been shaped by the challenge of living with Prader-Willi syndrome (PWS). Here's a brief overview of my experiences:

Education Journey:
I attended an integrated kindergarten and later an elementary school as part of a small group. I obtained my special school diploma at the Transnational School for Children with Disabilities. Following that, I spent a year at a vocational school for people with disabilities. Since my needs were not adequately met there, I decided to move to a group home in South Germany. In this group home, I live with nine others who also have PWS, spanning different ages. Our home is situated on the grounds of Regens Wagner Absberg, an idyllic resort with hills and lakes.

Interests and Hobbies:
Music: I've been playing the cello since age 5. My parents, both opera singers, instilled in me a love for theater, opera, and concerts.

Puzzles and Sudoku: I enjoy complicated puzzles and challenging versions of Sudoku.

Social Life: Having a godchild is essential to me. I actively participate in church activities.

Traveling: I have a passion for traveling, and I can find the best flight and train connections in no time.

Sports: Swimming has been a favorite activity since infancy. I also engage in cycling, walking, and bowling. Additionally, I keep fit with a rowing machine in my room.

My journey with PWS has been filled with challenges, but also with moments of joy, growth, and connection.

Lynn Garrick

Chair of the IPWSO Professional Providers and Caregivers Board, Programme Director, AME Community Services, USA
lynn@amecommunity.com

Lynn is the mother of 5 children, the youngest was diagnosed with PWS as an infant. She is a registered nurse and works as a program director for AME Community Services which is a residential provider for those living with PWS. In addition to her professional involvement with AME Community Services Inc., she has been a board member of the Minnesota Prader-Willi Syndrome Association for the past 17 years and serves as the medical and research coordinator for PWSA | USA.

Larry Genstil

Psychologist, Israel
genstil@gmail.com

Larry founded the Genstil Institute Hostel, Mevasseret Zion, Israel, where he served as Executive Director for over 30 years. Founded in 1991, the hostel is a large group home serving two populations, one of which is made up of adults with PWS. He partially retired in 2020 and now works in the group home several hours a week as a consultant. In addition, he is a Psychologist at the Multidisciplinary Clinic for People with PWS, Sha'are Zedek Medical Centre, Jerusalem, Israel, where he has worked since 1996, and is a long-standing member of IPWSO's Professional Providers and Caregivers Board.

Neil Gumley

Disability Professional, The Orange Hive, Australia
neil_gumley@hotmail.com

Neil gained a Science/Disability Degree from RMIT University in Melbourne, Australia in 2010 while at the same time working at the Department of Health and Human Services specialising in the management of Complex Behavioural Accommodation facilities. In 2014 Neil moved into the Operation Manager's role where he was tasked with establishing the first PWS specific accommodation in Melbourne, Australia. The facility has now been running successfully for over 10 years. In that time Neil has been appointed to the board of PWS Victoria, was nominated as the Australian Caregiver Delegate for the PPCB, served on the PPCB for the past 3 years and has attended both the Toronto and Cuban Conferences, the latter as a speaker. More recently, Neil has developed a new service/business focused on the Transition and Independent Development of people living with PWS.

Norbert Hödebeck-Stuntebeck

PWS-InterNational, Germany
nhs@pws-in.de

Dr Norbert Hödebeck-Stuntebeck is a Psychologist, Psychotherapist, and a Supervisor who resides in Bad Oeynhausen, Germany, where he served for 30 years as Project Manager PWS and Project Manager Adipositas (Obesity) for a large non-profit foundation in the northwest of Germany, in Northrhein-Westfalia. Today he leads the PWSInterNational Institut. He received his PhD in 2012 at the University of Eichstätt from a study about the competence of people with PWS in change of emotional perspective (empathy). Since 1996 he has been responsible for the development and differentiation of support for people with PWS of all ages and in different fields of living, working, school and training programs. He was, for 11 years, the chair of IPWSO's Professional Providers and Caregivers Board (PPCB) and is today a member of PPCB and was the (co)organiser of all IPWSO's caregiver conferences since the first in Romania in 2007. Since 2015 he has been the CEO of the Prader-Willi-Syndrom Institute Germany (PWS-ID). His interest in research is focused on empathy in PWS and the development and evaluation of training programs. Another field of interest is obesity.

Tony Holland

President of IPWSO, University of Cambridge, UK
tonyipwso@gmail.com

Tony Holland trained in Medicine at University College and University College Hospital, London, qualifying in 1973. After some years in General Medicine, he trained in Psychiatry at the Maudsley Hospital and Institute of Psychiatry in London. From 1992 to 2002 he held a University Lecturer's post in the Section of Developmental Psychiatry in the University of Cambridge, and in 2002 was awarded the Health Foundation Chair in Learning (Intellectual) Disability establishing the Cambridge Intellectual and Developmental Disabilities Research Group. His specific research interests include the eating, behavioural and mental health problems associated with having Prader-Willi syndrome (PWS). With colleagues he has published research extensively on these topics in academic and practice-based journals. He is Patron of the UK PWS Association and since 2016 he has been President of IPWSO. Since October 2015 he has held an Emeritus position at the University of Cambridge.

Brian Hughes

Professor of Psychology, University of Galway, Ireland
email: brian.hughes@universityofgalway.ie

Brian Hughes is Professor of Psychology at the University of Galway, Ireland, and is a Member of IPWSO's Advisory Group on Research on Specialist Services for People with PWS. He specialises in stress psychophysiology, health psychology, and research methods. He has conducted extensive research into the ways human cardiovascular responses habituate during repeated or sustained stress exposure, helping to explain how some people are resilient to the long-term effects of chronic stress. He has also conducted work with various patient groups, examining their experiences of medical and social care. He is a parent of a 20-year-old son who has Prader-Willi syndrome.

Nathalie Kayadjanian, Ph.D.

Scientific advisor, Raymond A. Wood Foundation, Trustee, IPWSO, USA
kayadjanian@gmail.com

Nathalie Kayadjanian, Ph.D is an expert in translational biomedical research for rare diseases with extensive experience in academia, biotech, and the pharmaceutical industry in Europe and in the USA. For the past several years, Nathalie has occupied top management positions in patient-driven non-profit research organisations including the Raymond A. Wood Foundation, Foundation for Prader-Willi Research, the French Association for Neuro-muscular disorders and the Amyotrophic Lateral Sclerosis Association where she developed and implemented strategies to accelerate the development of innovative therapies for rare diseases. She received her Ph.D in Neuroscience from the University Pierre and Marie Curie in Paris and did a postdoctoral training at the Salk Institute in La Jolla, CA. Nathalie has been a co-opted Trustee of IPWSO since 2022.

Laura Keane

Chief Executive, Resilience Healthcare, Ireland
lkeane@resilience.ie

Laura is the Chief Executive of Resilience Healthcare Ireland, a national private provider of services for people with disabilities. Laura is a registered Occupational Therapist, has an MSc in Health Services Management from Trinity College Dublin, and a diploma in Directorship. With over 30 years' experience working in the health and social care sector, her passion is in developing and delivering services and support that empower and enable people with disabilities to achieve their full potential. She is currently a voluntary Board Member of St. Gabriel's school, a centre in Limerick, Ireland which provides services for children with physical disabilities and Co-Chair of IPWSO's Professional Providers and Caregivers Board.

Myles Kelly

Project Manager, PWSA UK, UK
mkelly@pwsa.co.uk

Myles has been privileged to work with and support adults with PWS since 1986. Working for a national care provider, he saw the number of people supported grow from 3 in 1986 to almost 100 when he departed in 2022. As part of the team, Myles played a central role in developing, maintaining and improving the standards of PWS care and support, as well as keeping abreast of the latest news and insights from around the PWS world, by attending national and international conferences and training events. In all that time, he knew that he would simply never stop learning about PWS, no matter how many conferences attended nor how much he read. His role at PWSA UK from September 2022, sees him assessing how we can influence residential settings for adults with PWS to ensure they receive the best possible standards of care and quality of life, which will be hugely important to individuals and families across our community. Working for and with PWSA UK is the icing on his professional cake!

Maria Kirby

Maria Kirby, Head of Clinical Services, Resilience Healthcare. R.N.I.D., BA HRM., Pg Dip CBT, Developmental Trauma Informed Specialist, Ireland
maria.kirby@resilience.ie

Maria is a Registered Nurse in Intellectual Disabilities with 35 years' experience in the field of Intellectual Disability and Autism. Maria managed Clinical Disability Teams across Children's and Adult services for the past 20 years and she also managed children's respite services and developed Home Share Services. Maria is a qualified Human Resources Manager, a CBT Therapist and a Development Trauma Informed Specialist. Maria manages the Clinical Services Team in Resilience Healthcare and she has been instrumental in developing a Trauma Informed Disability Model of Care and developing service excellence in the areas of PWS, mental health, autism, intellectual disability, physical and sensory and genetic disorders.

Maria's particular area of interest is Person Centredness and supporting individuals around their choice-making, independence and quality of life within an informed and positive risk-taking framework.

Maria is currently undertaking her masters studies in Psychology with a view to conducting her thesis on "the impact of introducing and developing a Trauma Informed model of care to support the lives of service users and their families and to enrich the co-regulated relationships of individuals and their care staff ".

Svetlana Labun

Managing Director, EJF Hollerhaus gGmbH, Germany
labun.svetlana@gmail.com

Svetlana Labun holds a Ph.D. in adult education from the Catholic University of Eichstätt-Ingolstadt. She served as the Department Manager for special services, overseeing 73 individuals with Prader-Willi syndrome at Regens Wagner Absberg for 14 years. Additionally, Svetlana worked as a coach specialising in de-escalation and conflict management.

Since 2023, she has been the Managing Director at EJF Hollerhaus gGmbH in Ingolstadt—a facility that supports people with physical disabilities and complex multiple diagnoses. Svetlana has been associated with IPWSO since the 2007 Conference in Cluj-Napoca, Romania, and has actively participated in all subsequent IPWSO conferences. As of 2022, she holds the position of IPWSO Trustee.

Fred Nicolai

Chairman Prader-Willi Stichting, Netherlands
Voorzitter@praderwillistichting.nl

Fred Nicolai is stepfather of Iris who is 31 years old and lives with PWS. Fred is father of Mart (30), Jos (26) and Karst (22). In 2013, he and his wife, Mirjam, started the Prader-Willi Huis (Home) in the countryside in the north of the Netherlands. It turned out to be the beginning of an adventure that resembled a roller coaster ride. Today they have nearly 35 caregivers and 29 PWS clients living and working in four locations. Since 2019 Fred is the chairperson of the Dutch Prader-Willi Foundation. His main motivation is: united cooperation to achieve appropriate care for all people – young and old - with PWS.

Santiago Figueroa Pérez

COO, Palobiofarma, Spain
sperez@palobiofarma.com

Santiago joined Palobiofarma one year ago as Chief Operating Officer and is responsible for the development of the investigational medicines in Palobiofarma's portfolio. Santiago previously worked 23 years for Bayer Pharmaceuticals in Germany, where he held different positions in the research and development organisation, the last 5 years at Bayer he was the Head of Regulatory Affairs Cardiovascular and Thrombosis. Santiago is a Chemist by education with a PhD in Organic Chemistry from the University of Konstanz.

Vikacha Phiri

M.A., BCBA, LABA, Latham Centers Inc. Massachusetts, USA
vphiri@lathamcenters.org

Vikacha Phiri heads Latham Centers's children's program clinical department, located in Massachusetts, USA. She received her masters degree in psychology with focus in Applied Behavior Analysis in 2018 from the University of Massachusetts. A Board Certified Behaviour Analyst (BCBA) and Massachusetts licensed behaviour analyst (LABA); having worked with individuals with Prader Willi syndrome (PWS) for over a decade in various capacities starting from direct care. Vikacha is passionate about expanding use of core, evidenced based principles and techniques of Applied Behaviour Analysis (ABA) in areas outside of typically associated Autism. Additionally, she incorporates and considers an individual's private events, striving to create strength-based, person centered behaviour intervention plans.

Claire Poor-Harmon

Staffing Director, AME Community Services, Inc., USA
claire@amecommunity.com

Claire Poor-Harmon is the current Staffing Director at AME Community Services, Inc., a residential provider serving adults and children with Prader-Willi syndrome, where she has also served as a Direct Support Professional and Program Coordinator since 2016. Claire earned her Bachelor of Science degree from Truman State University in 2014 where she studied Health Sciences and Biology and is currently enrolled at Minnesota State University, Moorhead, where she will graduate with her Masters Degree in Healthcare Administration in the Spring of 2025. Claire is passionate about serving both PWS individuals and their caregivers with person-centered approaches that build and sustain supportive organisational networks and retention of PWS caregivers. In her personal life, Claire enjoys spending time traveling with her family and friends, camping in national parks, and many outdoor activities like ice fishing, in her home state of Minnesota.

June Sanson

Executive Director of Patient Advocacy & Industry Relations
Acadia Pharmaceuticals, USA
jsanson@acadia-pharm.com

June Sanson is an advocacy and industry relations strategic leader with over 24 years of experience in the biotech and pharmaceutical industry. She has held leadership roles in marketing, lifecycle strategy, and patient advocacy. She has expertise in rare diseases, neurology, and psychiatry. Her emphasis is patient engagement, quality of care, education, research, and improving outcomes for people living with rare and CNS related conditions. June studied Psychology at the University of California, Berkeley and lives in San Diego, California.

Janine Sinner

Team Leader, Caritas Upper Austria, Austria
janine.sinner@caritas-ooe.at

Janine Sinner has been working at Caritas Upper Austria since 2013, with the interruption of traveling abroad to acquire knowledge about PWS. She is team leader and co-founder of the PWS Competence Center Austria project.

Hubert Soyer, PhD.

Psychologist, Germany
soyer.hubert@gmail.com

Ph.D. in Psychology and Pedagogy from the Catholic University of Eichstätt-Ingolstadt, 2003.
Dissertation: Research on Social and Special Education for Prader-Willi Syndrome.
Diploma in Psychology from the Catholic University of Eichstätt-Ingolstadt, 1999.
Holds a teaching degree for elementary and secondary schools, including special education, since 1977.
Since 1999, has been a lecturer at the Chair of Social Pedagogy at the Catholic University of Eichstätt-Ingolstadt.
Former Managing Director of Regens Wagner Absberg (1994–2020, retired).
Since September 2022, serves as a consultant at EJF Hollerhaus gGmbH.
IPWSO Board Member: Served as a board member from June 2011 to November 2019.
Co-founder and member of the IPWSO Professional Providers and Caregivers Board (PPCB).
Organizer of the International Caregivers Conferences 2024 (Berlin), 2018 (Munich), 2012 (Wildbad Kreuth) and 2009/2008 (Herne) in collaboration with Dr. Norbert Hödebeck-Stuntebeck, PPCB and IPWSO board members and the IPWSO office.

Michelle Torbert

President, Friends of IPWSO (USA), USA
thetorbert7@gmail.com

Michelle and her Husband Tommy have been married for almost 38 years and have 4 grown sons, their daughter Leslie who is 26 years old with PWS and 4 grandchildren. They own a farming and produce company in which all their sons are employed.

Michelle has served on the board of PWSA/USA for 12 years, 3 of those in which she was board chair. She also is on the board of the Florida chapter for Prader-Willi syndrome in which she was president for 8 years. Michelle has been on the board for Friends of IPWSO since it's inception and is now President. She is also the Parent delegate to IPWSO for PWSA|USA. Michelle has served as co-chair for two PWSA|USA National conventions and presently serves on the Advocacy, Research and Finance committees.

Prior to having her children, Michelle served as a police officer/sergeant for the Homestead Police Department for 10 years. She has also served on the local hospital fundraising committee, Red Cross, Little Angels Foundation and her church board.

Michelle's passion lies with Prader-Willi syndrome both Nationally and Internationally.

Verena Wanker-Gutmann

PWS Austria, Chair, IPWSO Famcare Board, Austria
verenagutmann29@gmail.com

I developed the Austrian PWS Association and was chairperson for 10 years. I am a mother to a 34-year-old daughter with PWS. I was an IPWSO Board member from 2016-2022, and am the Chair of IPWSO's Famcare Board. I was an Educator and Head of the department and responsible for educational management of 100 adolescents. I was asked to focus on puberty issues, and I organised several talks and workshops. Subsequently I conducted lectures and workshops in organisations and colleges for caregiver education with a focus on "Handicapped sexuality". One of my interests now is to contribute to more PWS knowledge in Austria and advocating for PWS residences to be established in Austria.

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Our mission is to raise money to support IPWSO's programs.

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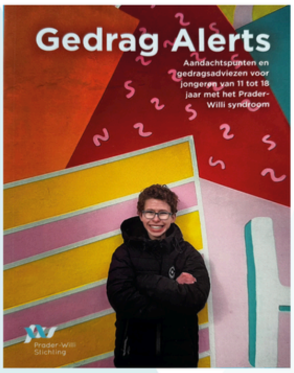
palo biofarma

Innovation through medicinal chemistry

Palobiofarma S.L. is a Spanish clinical stage biotech focused in developing new safe and effective therapies in areas of high unmet medical need. PBF-999 is an oral investigational medicine with a unique mode of action, that has the potential to control hyperphagia and related food seeking behaviors in individuals with PWS. Palobiofarma is conducting a Phase 2 study in Spain and plans to initiate a global Phase 3 trial in 2025.

Prader-Willi
Stichting

Prader-Willi Stichting is the patient organization in the Netherlands representing the interests of persons with Prader-Willi Syndrome and the people in their immediate environment such as parents, relatives and caregivers. The PWS community in the Netherlands is relatively small, but large enough to lobby governments, health insurance companies, researchers, hospitals, health care providers and other social organizations through education and information, peer contact, advocacy and international cooperation. We support this conference in Berlin because it's very important to exchange PWS expertise.



www.praderwillistichting.nl

Speaker overviews & abstracts

Day 1: Tuesday 21 May 2024

The Pam Eisen Lecture

The future of care for people with PWS

Norbert Hödebeck-Stuntebeck, PhD,
PWS-InterNational
Email: nhs@pws-in.de

In 2005, Pam Eisen, then President of IPWSO, recognised the need to integrate professional caregivers into the structure of the organisation as an increasingly visible and important part of the “world of care” for people with PWS. Over the next few years, she further developed this concept with committed cargivers from various countries, which ultimately resulted in the founding of IPWSO's Professional Providers and Caregivers Board (PPCB) during the 7th IPWSO conference in Taiwan.

At each Caregivers’ Conference, we take the time to honour Pam’s legacy, reflecting on the tremendous impact she made for caregivers and for those with PWS we support. This lecture will briefly outline the journey from the initial idea to the current standing of PWS caregivers within the wider PWS community. The main focus of the presentation will be ideas for future developments in the care of people with PWS.

Day 1: Tuesday 21 May 2024 continued

IPWSO’s initiative to give people with PWS a voice

Svetlana Labun, Managing Director, EJF Hollerhaus gGmbH, Germany
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The People with PWS Committee was established by IPWSO to empower individuals with Prader-Willi syndrome (PWS) to advocate for themselves. Through collaboration and research, the committee aims to create inclusive platforms for individuals with PWS to express their needs and aspirations globally. Looking ahead, the committee plans to enhance communication between IPWSO and international PWS groups, fostering self-advocacy and community engagement. Thanks to the inspiring contributions and intensive cooperation between people with PWS and the committee members, several groups were founded in different countries and the first interesting and forward-looking experiences were gained.

People with PWS give themselves a voice: Requirements and solutions (example of a group in Germany)

Christian Blohm, Metalworker, Germany

In 2022 IPWSO decided to start the initiative to involve people with PWS in the structures of IPWSO (Give people with PWS a voice). The main idea was, that people with PWS themselves develop the process of how to be involved. This presentation gives an overview about the way a group of people with PWS in Germany started this process of being involved in IPWSO. This group follows two main questions:

1. What are our main themes we wanted to bring into IPWSO?
2. How do we want to come in contact with IPWSO and in which way we want to discuss our ideas with and in IPWSO?

In this presentation the ways of working in the group will be presented and also the first results and future ideas will be described.

Outcomes for persons with Prader-Willi syndrome in full-time services: Findings from international archival data and future research directions

Brian Hughes, Professor of Psychology, University of Galway, Ireland
Email: brian.hughes@universityofgalway.ie

Despite the fact that full-time PWS-specific care is widely regarded as best practice, relatively few studies have directly examined the benefits of such services. We used archival data to investigate their impact. Data were supplied by providers of 11 full-time support services across 6 countries. The dataset included details on well-being and health, including weight, body mass index (BMI), and behaviours of concern (BOC), for a total of 193 people with PWS (ranging in age from < 10 yrs to > 50 yrs; 93% of whom were > 18 yrs).

We found that people with PWS showed significant reductions in weight, BMI, and BOC after joining a full-time care service. Improvements emerged within one year of entering, were cumulative over time, and were independent of age, initial weight, and BOC at entry. PWS-exclusive services were associated with greater improvements than mixed services. Improvements in outcomes appeared to lead to enhanced social contact among service recipients. The findings evidence the positive impact of full-time care services, especially if those services are specialised around the particular needs of PWS. The study highlights the benefits of collaborating to pool international data, as well as suggesting new avenues for future research.

Day 1: Tuesday 21 May 2024 continued

Operationalised list of infrastructure and staff skills required for specialised care of PWS as rated by residential care providers in the USA

Janice Forster[1], Lynn Garrick[2], Kim Tula[3], Linda Gourash[4], Stacy Ward[5], Ann Manzardo[6]

[1] Developmental Neuropsychiatrist, Pittsburgh Partnership, Pittsburgh, PA, USA
[2] Medical and Research Coordinator, PWSA I USA, Brandon, FL, USA
[3] Family Support Counselor, PWSA I USA, Brandon, FL, USA
[4] Developmental & Behavioral Pediatrician, Pittsburgh Partnership, Pittsburgh, PA, USA
[5] Interim CEO, PWSA I USA, Brandon, FL, USA
[6] Associate Professor of Pharmacology, Department of Psychiatry and Behavioral Sciences, University of Kansas Medical Center, Kansas City, KS, USA

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Introduction: Hughes et al. (2024) showed that a Prader-Willi syndrome (PWS) specific group home placement improves physical, behavioural, and social function of adults with PWS, highlighting the importance of controlled food access to improve weight and behavior. We sought to operationalise the essential constructs of care for PWS specific group homes.

Methods: A 48-item online survey about infrastructure, personal care, staff skills and attributes was developed by the authors and informed by the Best Practice Guidelines for Standard of Care of Adults with PWS in Residential Living. The survey was validated by two independent, on-line focus groups: (1) experienced providers of residential care for PWS and (2) parents managing their adults with PWS at home. The final survey was completed by staff working at group homes for adults with PWS.

Results: Survey items were highly rated and endorsed by both focus groups with 85% agreement. Staff respondents (N=38) had an average of 7 years of experience working in group homes serving PWS adults and had 89% agreement on survey items. Most group homes had 3-5 residents (78%) and were staffed 24 hours per day (82%).

Conclusion: The Residential Care Survey defines the infrastructure, personal care, and skills and attributes needed for group homes specialising in the care of adults with PWS. These survey items have operationalised essential guidelines for care in PWS group homes.

Day 1: Tuesday 21 May 2024 continued

Service involvement for children seen in the specialist PWS child mental health service in UK: Supporting a multi-agency approach to food security and wellbeing (and how restrictions can be liberating)

Dr Sarah Carman[1], Natasa Momcilovic[2], Yailin Acosta-Guzman[3], Dr Eleni Paliokosta[4] & Dr Sarah Bernard[4]

[1] Principal Clinical Psychologist
[2] Behaviour Therapist and PWS Service Lead
[3] Assistant Psychologist
[4] Consultant Psychiatrist

Organisation: National and Specialist CAMHS Specialist Prader Willi Syndrome Service, Mental Health of Intellectual Disabilities team, SCAAND, Michael Rutter Centre, South London and Maudsley NHS Foundation Trust, UK.

Introduction: Our service provides multidisciplinary assessment and intervention for children and young people with PWS and associated behavioural or mental health difficulties; we are the only specialist mental health service for children with PWS in the country. Psychoeducation, consultation and advocacy are central to our approach. This presentation aims to summarise service involvement for our patients, and share experiences of multi-agency working and good practice.

Method: A sequential audit of cases, identifying the presenting concerns, services involved and the team's contribution to multi-agency working. Representative case studies will be identified, reviewed and summarised.

Results: We will outline the services involved, relevant statutory UK frameworks and current health, education and social care provisions accessed by our client group. We will summarise data regarding the multi-agency work we completed and share a relevant case example, incorporating MDT reflections and patient, family-carer and professional perspectives.

Conclusions: Food security is an essential component of behavioural and psychological intervention, but can be difficult where challenging behaviour is also a concern. Close and consistent multi-agency working to ensure appropriate service provision is essential. Consultation from specialist clinicians with expertise in PWS can play an important role in this process. Whilst maintaining food security can require additional restrictive practices, the reductions in distress, food seeking and challenging behaviour may be associated with substantial increases in freedoms elsewhere.

Workshop overviews begin on Page 45

Day 2: Wednesday 22 May 2024

Overview of the Clinical Trials Process

Nathalie Kayadjanian, Ph.D. Scientific advisor, Raymond A. Wood Foundation, Trustee, IPWSO, USA

Email: kayadjanian@gmail.com

Clinical trials have been fundamental in fostering the development of novel treatments in medicine and for understanding disease mechanisms. During the last 10 years, the number of clinical trials testing new drugs for PWS has increased significantly. Drugs with different mechanisms of action are being tested opening avenues for better understanding the biology underlying PWS. While this raises the hope that new treatments will be available soon, there are a number of challenges and barriers at each stage of the therapeutic development process that could impede successful clinical trials outcomes and access to meaningful therapies for individuals with PWS.

In this talk Nathalie Kayadjanian will present an overview of the clinical trial process. We'll explore the process of clinical trials, opportunities and challenges, and how to get information about trials and advocate for individuals/guardians for those that wish to and are able to participate.

Research and Clinical Trials Update

In this session we'll hear information on current, planned, and recently concluded trials for PWS, and discuss the barriers and/or opportunities for participation for those living in social care settings.

Moderated by: Tony Holland, IPWSO President, University of Cambridge UK

Acadia Pharmaceuticals Clinical Trial Program for Prader-Willi Syndrome

June Sanson, Executive Director of Patient Advocacy & Industry Relations,
Acadia Pharmaceuticals, USA

Email: jsanson@acadia-pharm.com

Acadia Pharmaceuticals initiated a phase 3 global clinical trial program to study hyperphagia in Prader-Willi syndrome. This presentation provides an overview of Acadia, the phase 3 clinical trial program, and how people with PWS living in residential services might become involved in the trial.

Day 2: Wednesday 22 May 2024 continued

PBF-999: Development of a novel therapy to treat hyperphagia in PWS

Santiago Figueroa Pérez, COO Palobiofarma, Spain
Email: sperez@palobiofarma.com

PBF-999 is a novel potent PDE10 inhibitor in phase 2 development to reduce hyperphagia in patients with Prader-Willi syndrome. PDE10 inhibition represents a novel target that has the potential to reduce the hyperphagia associated with the PWS, by reducing the drive for compulsive food seeking, thus reducing the subsequent weight gain, and improving the behavioural aspects related to the insatiable appetite. It may also have several metabolic benefits reducing the risk for developing diabetes.

Palobiofarma S.L. is developing PBF-999 as an oral therapy for chronic use to add on to the current treatment algorithm to reduce hyperphagia in paediatric and adult patients suffering from PWS. To date, there is no approved pharmacological therapy for reducing appetite in patients with PWS. Currently, Palobiofarma S.L. is conducting a phase 2 study in Spain, which is a double-blind, randomised, placebo-controlled, crossover study comparing a 28-day treatment with PBF-999 vs. placebo followed by a voluntary open-label extension phase for the patients who wish to continue treatment beyond the double-blind phase. Ten patients planned for the first cohort (40 mg QD) already completed the blinded crossover phase and six of them also completed the open-label phase. Three patients are still on treatment in the open-label phase. Based on the results of the 40 mg QD cohort, Palo Biofarma S.L. decided to open enrolment in the second cohort, where 10 more patients will receive PBF-999 40 mg BID and matching placebo.

Based on the encouraging results of the first cohort, Palobiofarma is in conversations with the FDA and EMA to design a phase 3 study in adult and paediatric patients with PWS, that is planned to start in the second half of 2025.

Update on the clinical development program for DCCR in Prader-Willi Syndrome (PWS)

Dr. Dairine Dempsey, VP, Europe, Soleno Therapeutics Inc., Ireland
Email: dairine@soleno.life

Diazoxide choline extended-release (DCCR) tablets are being developed for the treatment of people with Prader-Willi syndrome (PWS).

DCCR has been evaluated in a series of Phase 1, Phase 2 and Phase 3 studies, 3 of which were in people with PWS. DESTINY PWS (C601) was an international randomised, placebo-controlled Phase 3 clinical trial that enrolled participants with PWS ages 4 and older with hyperphagia. C602 was an open label long-term safety and efficacy study (OLE) with a double-blind, placebo-controlled randomised withdrawal period (RW). The primary efficacy endpoint of C601 and C602 was Hyperphagia Questionnaire for Clinical Trials (HQ-CT) change from baseline. Other endpoints included clinical and caregiver assessment of improvement or change, body composition measurements by DXA, other behavioural assessments and changes in hormonal and endocrine parameters.

In addition, data from a cohort of participants from C601/C602 have been compared to a matched cohort from the PATH for PWS (PATH) natural history study of participants with PWS age 5 and older conducted by the Foundation for Prader-Willi Research.

This presentation will provide updated information on the DCCR development program at the time of the conference.

Day 3: Thursday 23 May 2024

Meaningful employment for people with PWS

Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel
Email: genstil@gmail.com

Historically, people with PWS worked primarily in sheltered workshops, where there was always the possibility of close supervision regarding food and behavioural issues. Of late, there have been various programs in some countries in which people with PWS have been involved in vocational training, placement in regular work settings, and have also attended college.

In Israel, we have been implementing some of these programs for the past 5 years, approximately, with some degree of success. Most of the workers have been on the higher range of cognitive functioning and many older (30s to 40s). It seems that many people in this age range have developed more behavioural control and if there is a degree of supervision, they also are able to limit their food seeking behaviours.

Unfortunately, many of these programs were disrupted due to COVID. However, the basis of the program was to have each participant go through an in-depth vocational evaluation, the results of which would lead to vocational planning. For some of the participants, they would continue in more supervised settings. However, those with borderline and above cognitive functioning and appropriate behavioural control were to receive vocational training and placement in groups in more regular work settings. This program was implemented over the course of 3 years until COVID interrupted the program. It has been difficult to rebuild such a program but we are attempting it piecemeal.

My goal in pursuing this area is to develop a Best Practices guide for meaningful employment for people with PWS.

Network Switzerland

Bastian Bühler, Social educator/Team leader, Stiftung Arkadis, Switzerland
Email: bastian.buehler@arkadis.ch

The collaboration among Swiss Prader-Willi syndrome residential groups is distinguished by the following features:

- Regular professional exchange among staff members to facilitate knowledge sharing and development.
- Consistent Prader-Willi syndrome-specific training involving all groups, including case studies and practical applications.
- Integration of the second life domain work.
- Joint holiday events organised across the three groups to promote social interaction and community inclusion.
- Exchange of clients or "room swapping" among groups.
- Constant cooperation with and unified representation to the Prader-Willi Syndrome Parents' Association.
- Establishment of a jointly managed national waiting list for clients seeking placement in Prader-Willi syndrome residential groups, streamlining the admission process and ensuring equitable access to services.

Day 3: Thursday 23 May 2024 continued

PWS Competence Center Austria

Janine Sinner, Team Leader, Caritas Upper Austria, Austria
Email: janine.sinner@caritas-ooe.at

Janine Sinner will present on the PWS Competence Center Austria, how it came about, how it is progressing now, and their vision for the future.

Panel discussion: Self-determination, self control: Opportunities and limitations

Moderated by: Hubert Soyer, Psychologist, Germany
Lee Chamberlain, VP & Chief Strategy Officer, Latham Centers, Inc., USA
Maria Kirby, Head of Clinical Services, Resilience Healthcare, Ireland
Fred Nikolai, Chairman Prader-Willi Stichting, Netherlands
Michelle Torbert, President, Friends of IPWSO (USA), USA

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All delegates are encouraged to participate by sharing opinions and asking questions as part of this panel discussion session.

Questions & Answers: Your medical questions

Moderated by: Lynn Garrick, Programme Director, AME Community Services, USA
David M. Agarwal, MD, FSIR, Indiana University School of Medicine, USA
Susanne Blichfeldt, MD, The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark
Janice Forster, MD, Developmental Neuropsychiatrist, Pittsburg Partnership, Pittsburgh, PA, USA

Emails: lynn@amecommunity.com, s.blichfeldt@dadlnet.dk, janiceforstermd@aol.com

Interactive session where delegates will have the opportunity to pose questions on medical care for people with PWS. Delegates with medical expertise are also invited to share their advice during the session.

Panel discussion: What supports are available for people with PWS who overburden the system with their challenging behaviour? Models and limits

Patrice Carroll, Director of PWS Services, Latham Centers, USA
Lynn Garrick, Programme Director, AME Community Services, USA
Larry Genstil, Psychologist, Executive Director, Genstil Institute of Human Behaviour, Israel
Myles Kelly, Project Manager, PWSA UK
Moderated by: Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany

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All delegates are encouraged to participate by sharing opinions and asking questions as part of this panel discussion session.

Workshops

Therapy options | Day 1

Art as a therapeutic approach for people with Prader-Willi syndrome

Workshop leader: Tovi Florsheim, Israel

Email: tovigen@gmail.com

People with PWS have many behavioural issues such as OCD, argumentativeness, rage outbursts, emotional management difficulties, control issues, and anxiety. The amount of emotional load they carry due to the emotional outcomes of the syndrome can be extreme. The need for emotional therapy that will help them to unload, face and acknowledge those feelings is necessary.

Due to limited auditory perception of people with PWS, conventional therapy has a limited value. On the other hand, people with PWS have good visual perception and we can utilise that strength for emotional therapy through art. Using art as a therapeutic tool allows the individual with PWS to be able to connect to the self, to express himself/herself, fulfill the basic need to be seen and leave a hand print, improving self-image, self-satisfaction, and success – things that through classical verbal therapy will be less achievable.

Some of the people with PWS have trouble understanding abstract concepts and therefore, they will struggle to understand their feelings and express them. Through the experience and the presence of an actual product, there is a concrete and visual manifestation of those emotions that allows a therapeutic conversation about them, among other therapeutic processes.

Matching the type of therapy to a person with PWS will prove more effective and have higher success rate. Using art as a therapeutic tool can increase their confidence, sense of existence, improves self-image, satisfaction, relaxation, sense of accomplishment, self-expression, choice, and sense of control. These feelings are a great foundation for behavioural improvement and better quality of life. I would like to share by allowing you to experience this powerful approach of art therapy for people with PWS, raise awareness with the caregiver community, and encourage the use of it.

Therapy options | Day 2

Applied Behaviour Analysis

Workshop leader: Vikacha Phiri, M.A., BCBA, LABA, Latham Centers Inc. Massachusetts, USA
Email: vphiri@lathamcenters.org

This workshop caters to caregivers and professionals caring for individuals diagnosed with Prader Willi syndrome (PWS), aiming to highlight the strategic integration of Applied Behaviour Analysis (ABA) into daily behaviour management. Attendees will identify proactive strategies rooted in behaviour analysis already incorporated into therapeutic practice and how the application of principles and techniques of ABA further enhances therapeutic treatment in individuals with PWS.

Key focuses include identifying existing behaviour analytic strategies employed in therapy and understanding their effectiveness. Moreover, participants will explore the customisation of behaviour management approaches for individuals with PWS, fostering independence and improving overall quality of life.

Both informative and interactive, the workshop begins with a presentation overviewing basic concepts of ABA including thorough assessment, individualised behavioural intervention planning, and skills building. Subsequently, attendees will have the opportunity to apply knowledge covered in the presentation in small break-outs. This hands-on approach allows participants to build and strengthen connections surrounding how behaviour analytic assessment and intervention can be a core component of strength-based, person-centered intervention planning that is tailored to individual needs.

By the workshop's conclusion, attendees will be equipped with practical knowledge and a deeper understanding of how incorporation of strategies and principles of ABA can have positive impacts on effectively in their caregiving roles or professional practice. This interactive session promises to empower participants with actionable insights to enhance the lives of individuals with PWS through individualised behaviour management.

Balancing rights and restrictions for individuals with PWS

Workshop leaders: Hubert Soyer, PhD. Psychologist, Germany, Gary Brennan, National Development Manager, PWSAI, Ireland and Lynn Garrick, Programme Director, AME Community Services, USA

Emails: soyer.hubert@gmail.com, gary.brennan@pwsai.ie, lynn@amecommunity.com

This workshop invites all participants to a dialogue to find practical solutions for a central and particularly sensitive issue in dealing with Prader-Willi syndrome (PWS). The workshop comprises four keynote speeches in which basic concepts are presented that serve as a basis for the subsequent discussions. These ideas will be integrated into the framework of the workshop.

The participants will jointly develop a catalogue of discussion points, which will be prioritised according to their importance. These topics will then be explored in greater depth in small working groups. The insights gained from these focused discussions will be recorded as the final outcome of the workshop.

In the short presentations, the topic will be examined from different angles to ensure a comprehensive understanding of the complex interrelationships.

Workshop presentations:

Introduction: Balancing individual rights and restrictions - an irresolvable dilemma

Hubert Soyer, Germany

Is a balance between the individual rights of a person with PWS and (necessary?) restrictions possible or should there rather be a dialogue on how to deal with tensions between individual rights and restrictions that arise.

Focal points are autonomy vs. protection, access to food and nutritional control, integration vs. protection from overstimulation, right to education and employment, to name but a few.

Balancing rights and restrictions for individuals with PWS

Johannes Furhman, Germany

This presentation discusses the challenges of balancing rights and restrictions for individuals with Prader-Willi syndrome (PWS). Highlighting personal experiences, it emphasises the importance of independence and the barriers faced in realising aspirations. The talk advocates for a paradigm shift in caregiving, focusing on nurturing individual potential and empowering individuals with PWS to lead autonomous lives. Collaboration between caregivers and individuals with PWS is essential to bridge the gap between aspiration and reality, fostering inclusivity and empowerment.

Balancing rights and restrictions for individuals with PWS (continued)

Workshop presentations:

Balancing rights and restrictions

Lynn Garrick, USA

For many providers across the globe, there can be a tension between rights and restrictions. We may hold tight to our own personal beliefs of what is the best way to support individuals. This may come from past experiences, generalisations, or what we have been taught in the past is the way to successfully manage PWS. Sometimes providers can become stuck in a pattern which begins with a deficit mindset. Each person is unique and will not need the same level of restrictions or support. Taking the time to fully understand each individual you support is key.

Restrictions may be necessary to maintain health and safety. Conversely, restrictions can bring about behaviours and cause dependence. Does supporting individuals with PWS always include restrictive practices like limiting access to food and money?

Before initiating any restrictions, we must consider the UNCRPD and how we can support the individual to lift the restrictions.

This presentation will look at ethics when deciding on rights restrictions, addressing our biases, the fear some of us may have when “loosening the reigns” and how to be a partner in support.

Decision-Making Capacity and PWS.

Gary Brennan, Ireland

In April 2023 the Assisted Decision Making (Capacity) Act (2015) was enacted into legislation in Ireland. The Act supports decision-making and maximises a person’s capacity to make decisions. It applies to everyone over the age of 18 and is relevant to all health and social care services. This Act will help comply with human-rights obligations including the United Nations Convention on the Rights of Persons with Disabilities.

In terms of decision-making, adults with PWS can make decisions about many areas of their life, but dysfunction in areas of the brain that control eating behaviour and energy balance means that may struggle to have the capacity to independently make decisions about eating.

My presentation will look at how the Prader-Willi Syndrome Association of Ireland are working with local agencies to identify a framework of supports for adults with PWS and their families, that meets their needs around their capacity to make informed decisions and also works within the scope of the legislation.

Friends, partnerships and sexuality in PWS

Workshop leaders: Patrice Carroll, Director of PWS Services, Latham Centers, USA and Neil Gumley, The Orange Hive, Australia
Emails: pcarroll@lathamcenters.org, neil_gumley@hotmail.com

This workshop on friendships, partnerships and sexuality will focus on the unique challenges that people with PWS face in forming and maintaining friendships as well as navigating their sexuality. Discussions will center around healthy relationships, addressing social deficits and creating an appropriate education in relation to sexuality. An emphasis will be on the importance of effective education, communication and the dignity of risk.

Understanding behaviour: Behavioural diagnostic methods for caregivers in the everyday support of people with PWS and the implications for interventions

Workshop leaders: Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany and Tony Holland, Psychiatrist, University of Cambridge, UK
Emails: nhs@pws-in.de, tonyipwso@gmail.com

This workshop will focus on two main topics:

1. The use of standardised diagnostic procedures that can provide helpful background information for understanding the behaviour of people with PWS.

2. The development and evaluation of observational methods that can be used in everyday care.

The aim is to develop more reliable and objective information about the basis or background for challenging behaviour affecting people with PWS. The results of the methods discussed form the basis for targeted support and interventions in the support of people with PWS. Examples of such methods will be presented and the participants will be asked to draw on their own experiences during the workshop.

During the course of the interactive sessions brief lectures will be given to provide some additional basic information to support the diagnostic process. These will include presentations on the following:

- Subjectively perceived wellbeing
- Mental illness and PWS
- Behaviour analysis
- Physical illnesses in PWS

Ageing in PWS

Workshop leaders: Larry Genstil, Psychologist, Executive Director, Genstil Institute of Human Behaviour, Israel and Susanne Blichfeldt, MD, The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark
Emails: genstil@gmail.com, s.blichfeldt@dadlnet.dk

This workshop will begin with a group discussion wherein delegates can share what they hope to learn from the workshop, and how they wish to work together to draw conclusions and make recommendations for the care of ageing people with PWS in residential services.

There will be a presentation about physical ageing in PWS (see abstract below) and a presentation about mental health and ageing in PWS. We'll also focus on the changing needs of people with PWS as they age, and what happens when the family is no longer present.

There will be ample time for discussions on various themes about ageing in PWS and the groups will present their thoughts and recommendations to each other. We'll also plan for future communication, strategies, research, and more. Final conclusions will be written, to be shared with the wider PWS community after the conference.

Workshop presentation:

Ageing in Prader-Willi Syndrome: Medical conditions and diseases to be treated

Susanne Blichfeldt, MD
The Danish Prader-Willi Association, IPWSO Clinical and Scientific Advisory Board (CSAB), Denmark

Introduction: Prader Willi syndrome (PWS) is a complex disease. Thanks to growing knowledge, treatment possibilities and care, persons with PWS now survive into adult age and can live years healthy and happy, and face the possibility of becoming “old” and then need extra support.

Methods: Many treatable symptoms in PWS are well known. We need more systematic investigations about how adults are actually treated in various countries, how often they have medical contact and which medical treatment is given. We know from the general population that diseases often found in PWS, if untreated, can cause early ageing, reduced lifespan and perhaps dementia. Conditions to be aware of in PWS are: Hypogonadism, growth hormone deficiency, hypothyroidism, diabetes, obesity that causes heart and circulatory problems, respiratory diseases including sleep apnea, vitamin deficiency and physical inactivity.

A recent Dutch investigation * showed that among 115 adults with PWS 61% had one or more untreated health problems, and 25% had multiple untreated health problems.

Psychiatric diseases can arise and be treated. Dementia is not a common symptom in PWS, but if suspected testing and care is possible.

Due to ageing, new needs and symptoms can arise and individual support is always needed.

Conclusion: Knowing symptoms and diseases that can be seen in PWS, and knowing from the general population the effect on ageing and survival if these conditions are not treated, it is recommended that all with PWS regularly receive lifelong medical evaluation and treatment together with continuous information and counselling for caregivers and families. A proposal for systematic medical contact will be presented.

*Reference:
Pellikan K et al: Missed Diagnoses and Health Problems in Adults With Prader-Willi Syndrome: Recommendations for Screening and Treatment
The Journal of Clinical Endocrinology & Metabolism, 2020, Vol. 105, No. 12, e4671–e4687

Staff retention: and what happens when there is a breakdown?

Workshop leaders: Lynn Garrick, Programme Director, AME Community Services, USA and Claire Poor-Harmon, Staffing Director, AME Community Services, USA
Emails: lynn@amecommunity.com, claire@amecommunity.com

Introduction: Individuals with Prader-Willi syndrome do best when there is structure and consistency. Maintaining stable staffing is critical to the success of PWS individuals and organisations. When retention rates fall or key people within the organisation leave, it brings about organisational instability that negatively effects the employees and the individuals they support. An employee retention strategy should be a fundamental part of any organisation.

Methods: During this interactive presentation we will discuss caregiver retention and organisational sustainability through using a data driven, employee centered systematic approach.

Key topics include:
- The four pillars of retention
- How breakdowns happen and how to pro-actively approach issues
- Strategies to get back on track
- Developing a personalized retention strategy
- Using data metrics to identify workforce shortages and track for improvement
- Creating a robust new hire onboarding program
- Leadership styles & manager roles in staff retention
- Investing in & empowering employees

Conclusion: Through creating positive and engaging work environments, supporting caregiver needs, providing employees with growth opportunities, and focusing on recruitment and retention of caregivers, an organisation can make great strides towards workforce development improvements. Understanding the components of staff retention and formulating an individualised plan can help with organisational sustainability and overall consumer satisfaction. This involves person-centered approaches for both employees and consumers as an integral part of an organisation’s mission, vision, and values to support overall job satisfaction and longevity.

Workshop presentation:

Staff turnover in PWS organisations (group homes)

Verena Wanker-Gutmann
PWS Austria - Chair, IPWSO Famcare Board, Austria
verenagutmann29@gmail.com

Staff turnover in PWS organisations is a big challenge for all persons involved. As the mother of a 34 year old daughter with PWS who has lived and worked for more than 10 years in a residence in Germany, I will talk about our experiences and possible preventions of specific issues.

Poster abstracts

“Caregivers Work”
Outline between current state and future perspectives

Cornelia Anzengruber, BA

Leader of PWS Department, Sozialwerke Clara Fey, Austria

Email: Anzengruber@sozialwerke-clara-fey.at

Abstract:
The adult living area offers different types of living for adults, including a shared apartment with a focus on Prader-Willi syndrome (as part of full time care).

There are currently 6 people with Prader-Willi syndrome living in a shared apartment at the location.

In addition, there is a detached single apartment for one person, which is located near the facility and can be reached on foot.

The shared apartment was opened in 2019 and since then we have been able to gain a lot of experiences with the PWS diagnosis and create a small network across Austria.

Big thanks go to the international experts in the field of PWS, especially Germany.

Focus for the future:
Over the years it has become clear what our focus is for the future.

We want to enable people with PWS to lead a self-determined life and manage the balancing act between rights and necessary restrictions in order to maintain health for as long as possible.

In the poster presentation we would like to briefly present the current situation with the challenges that the future will bring.

We hope you will all join us for the Poster Presentation session on Day 1 of the conference, and/or take the time to view the posters and speak to the presenters during breaks.

The posters can also be viewed as a PDF on the conference website:
https://ipwso.org/news-events/ppcconference2024/conference-posters/

Analysis of the relationship between Sensory Processing and some dysfunctional behaviours, with particular reference to Food-related Behaviours and Autism Spectrum Disorder-Like Behaviours in Prader-Willi Syndrome

Serafino Buono[1], Paola Occhipinti[2], Marinella Zingale[3], Angela Antonia Costanzo[4] & Donatella Greco[5]

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Abstract:
Prader-Willi syndrome (PWS) is characterised by considerable phenotypic complexities, some of which are aberrant behaviours, food related behaviours and, in some individuals, autistic-like behaviours that affect the quality of life of entire family system.

It is reported in the literature that individuals with PWS demonstrated abnormalities in sensory responsiveness and present sensory difficulties across behavioural, functional and quality-of-life outcomes. Nevertheless the relationship between sensory processing and ASD-like and associated behaviors in individuals with Prader-Willi syndrome (PWS) remains relatively unexplored. This work aims to study and identify the level of sensory processing dysfunction, examining and comparing it with the severity of food-related behaviours and aberrant behaviors.

To this end, to investigate autistic-like characteristics, eating behaviuor and sensory processing, a group of parents of pre-school and school age children were asked to complete the following check lists: Social Responsiveness Scale - Second Edition (SRS-2); Sensory Processing Measure (SPM) pre-scholar and scholar version, and Children's Eating Behaviour Questionnaire (CEBQ). The findings of this pilot study support the importance of proper assessment for early sensory integration intervention in order to prevent many dysfunctional behaviours often related to the behavioural phenotype of Prader-Willi syndrome.

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A case of Angelman Syndrome from a mother with Prader-Willi Syndrome

Donatella Greco[1], Letizia Ragusa[2], Paola Occhipinti[3], Antonella Costanzo[4], Loredana Nucifora[5], Francesco Calì[6], Serafino Buono[7], Corrado Romano[8]

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Abstract:

Prader-Willi syndrome (PWS) and Angelman syndrome (AS) are neurodevelopmental disorders caused by lack of expression of imprinted genes in the PWS/AS critical region 15q11-q13. The clinical features of PWS include hypotonia and feeding difficulties at birth, followed by delayed psychomotor development, hyperphagia resulting in obesity. Other reported characteristics are peculiar facies, very small hands and feet, intellectual disability, learning difficulties, behavioral disorders or serious psychiatric problems, hypogonadotropic hypogonadism with pubertal development delayed or incomplete. Infertility is a constant feature in both sexes of PWS. We report the case of a 25-year-old woman with PWS and her 3-month-old daughter with AS. PWS was confirmed at the age of 8 years by molecular genetic investigation which highlighted a deletion of paternal origin of ~4.6Mb in the 15q11.1-15q13 region (Type II). Molecular genetic analysis in the daughter demonstrates the maternally inherited deletion of the same region. In the literature, six women with PWS who have procreated are described and only in one case is there documentation of the birth of a child with AS. Our case confirms the non-Mendelian inheritance of PWS and AS and provides further evidence of possible fertility in PWS women. We suggest that it is important for PWS women to receive sexual education, to carefully evaluate their fertility conditions in order to potentially access contraceptive methods and genetic counseling.

We hope you will all join us for the Poster Presentation session on Day 1 of the conference, and/or take the time to view the posters and speak to the presenters during breaks.

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People with Prader-Willi-Syndrome in a work context - A qualitative-explorative study to develop recommendations for considering syndrome-specific characteristics

Jana Ivancevic

Business Psychology Student (Bachelor of Science); Event & project management, administration. Prader-Willi-Syndrom Vereinigung Deutschland e.V., Cologne, Germany

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Introduction:
This bachelor thesis explored how the characteristics of individuals with Prader-Willi syndrome, a rare genetic disorder, can be accommodated in a work context. The aim was to generate recommendations which can be used to create successful employment relationships.

Methods:
The required information was gathered through qualitative research design using expert interviews. The sample consisted of six experts from various institutions, in different positions, and with diverse educational backgrounds. The structured content analysis method by Mayring was used for systematic evaluation of the information.

Results:
Overall, it was found that almost all characteristics of individuals with Prader-Willi syndrome are relevant in the work context. This led to a large number of potential recommendations, which should be individually selected, as Prader-Willi syndrome can vary from person to person. Key factors for successful employment include clear structure, food security, specialised nutritional management, and a specially trained contact person with whom a good relationship is maintained. Employment in the primary labor market can be possible if both the individual and the workplace meet certain conditions. Furthermore, challenges and possible solutions were considered.

Conclusions:
As a whole, this work confirmed many findings from previous publications but also provided new information that could be used both as a basis for further research and in practice.

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Mental Well-being of Siblings of Individuals with Prader-Willi Syndrome: A Mixed Method Approach

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Introduction: Prader–Willi syndrome (PWS) is a rare neurodevelopmental disorder with an estimated prevalence of 1 in 20,000. Individuals with PWS require extensive support which can place stress on family members. This study aimed to explore the mental well-being of adults who grew up with a sibling living with PWS.

Methods: A mixed method design was employed to collect data over two Phases. 37 siblings without PWS participated in Phase 1, which involved the completion of an online survey profiling their mental well-being. 9 of these siblings participated in Phase 2, which involved one-one interviews to further explore their mental health experiences.

Results: Among the 37 siblings who completed the survey, 48.6% reported that their mental health had been affected, which had a causative relation to their sibling with PWS. Additionally, siblings who grew up in a stressful home environment, experienced decreased parental attention and/or had a sibling with PWS who self-harmed, were significantly more likely to develop anxiety, but not depression. Within the interviews, 6 themes were identified: (i)Childhood Impact, (ii)Positive Experiences, (iii)Social Experiences, (iv)Impact on Relationship with Parents, (v)Mental Health Impact (vi)Future Worries.

Conclusion: According to this study, growing up with a sibling with PWS significantly increases anxiety in unaffected siblings, however not depression. Results highlight the substantial need for more supports for siblings of individuals with PWS.

We hope you will all join us for the Poster Presentation session on Day 1 of the conference, and/or take the time to view the posters and speak to the presenters during breaks.

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Prader Willi and Computer Programming: a clinical case

Silvestro Maccarrone[1], Paola Occhipinti[2], Angela Antonia Costanzo[3], Francesco Domenico Di Blasi[4], Maria Agatina Stimoli[5], Serafino Buono[6]

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Introduction: Teaching computer programming represents an innovative rehabilitation practice as it allows people with Prader Willi syndrome (PWS) to be able to express their potential skills, if appropriately stimulated.

The objective of this study is to present a computer programming structured learning path addressed to a young adult with PWS and Intellectual Disability (ID).

Method: The activity was carried out at the multimedia educational laboratory of the Oasi Research Institute (Troina, Italy). For this purpose, an authoring software (Jclic) was used which easily allows to create teaching exercises based on the specific profile of cognitive and adaptive functioning, usable and replicable in the various areas of development (daily life, play, communication, accessibility, school learning, etc.). A teaching procedure including a baseline was implemented; a training phase with the use of most to least prompts (from the most intrusive to the least intrusive) and a follow-up after a month, to verify the maintenance of the acquired skills.

Results: The results show that the PWS subject acquired the programming skills and was able to complete the procedure independently.

Conclusions: The learning of these skills could be encouraged as part of occupational autonomy paths and of the broader life project of people with PWS.

We hope you will all join us for the Poster Presentation session on Day 1 of the conference, and/or take the time to view the posters and speak to the presenters during breaks.

The posters can also be viewed as a PDF on the conference website:
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Mindfulness-based intervention for individuals with Prader-Willi Syndrome and their parents

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Introduction: Individuals with Prader-Willi syndrome, can exhibit problem behaviours thus posing real challenges to their parents.

Mindfulness-Based Interventions (MBI) can be used to help PWS parents and caregivers to more effectively cope with challenging behaviours and manage stress-related disorders which usually affect caring functions.

Aim of our study is to verify whether mindfulness practices can help parents reduce stress levels as well as increasing emotional and behavioural self-regulation in PWS individuals.

Methods: The intervention protocol was addressed to 10 individuals with PWS and 10 parents, recruited at Oasi Research Institute. The intervention was structured into 10 sessions, one per week, consisted of awareness practices, psycho-educational treatment and weekly homework. At the baseline and at the end of the intervention, each parent were administered: IM-P; PSS; CBCL or ABCL; PWSBQ.

Results: With regard to the parents pre-and post data comparison showed statistically significant differences in Non-reactivity scale of IM-P ($p = .023$), in the Total Score of PSS ($p = .012$). Regarding the PWS individuals, the results showed a statistically significant change in the dimensions referred to Thought Disorders of CBCL/ABCL ($p = .018$), in the Total Score ($p = .034$), and in the area of Oppositional Behaviours and Interpersonal Problems ($p = .046$) of the PWSBQ.

Conclusions: Based on the data obtained, we believe that mindfulness-based parenting intervention can help to reduce parenting stress and improve well-being.

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Behavioural changes in patients with Prader-Willi syndrome can mask severe physical illness

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Introduction:
Behavioural and psychiatric problems are common in patients with Prader-Willi syndrome (PWS), while physical complaints such as pain, fever and vomiting are rare due to a high pain threshold and dysregulation of temperature control. Additionally, PWS patients have an increased mortality rate, some due to undiagnosed life-threatening diseases.

Methods:
In this case report, we describe two patients with PWS whose behavioural changes, initially thought to be part of their behavioural phenotype, delayed the final diagnosis of a life-threatening underlying illness.

Results:
A thirteen-year-old girl with PWS presented with a sudden change in behaviour including aggression, scratching and self-injury. She was seen by several health care providers, and after five months she was ultimately diagnosed with a pyosalpinx, for which laparoscopic resection of an infected tailgut cyst was performed, resolving the behavioural symptoms. A 38-year-old man with PWS presented with recurrent vague inguinal pain, behavioural problems and non-epileptic seizures. After several years of consulting physicians and psychiatrists, including several hospital admissions, the diagnosis of bilateral inguinal hernia was made. After surgical correction, the pain and seizures ceased.

Conclusion:
In PWS patients presenting with unexplained behavioural changes and unusual somatic complaints, clinicians should perform an extensive clinical examination and consider underlying physical illness rather than attribute the problem to the behavioural phenotype.

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Travel grant scholarships

With generous support from Friends of IPWSO (USA), IPWSO was delighted to offer travel scholarships to the following individuals to enable their attendance at the 6th International PWS Caregivers' Conference.

Maria Benedekova

PWS Slovakia, German/English to Slovak Translator, Slovakia

I am a freelance translator of German and English to Slovak language. My hometown is Košice, the second biggest town in Slovakia, with population of about 250,000 people. In 2006, I was one of the founding members of the PWS organization in Slovakia.

I am a mother of a 22-year-old son Tomas who has PWS. After completing his education in 2022, Tomas started attending a day care center for individuals with special needs in our hometown where my husband works as a care provider.

At the conference in Berlin I hope to collect some tips about daily routines for young adults with PWS living in a residential setting that we could use in the day center our son visits. There are two more young adults with PWS visiting this facility. I hope to hear about some approaches from experienced professional care providers who work with young adults with PWS on how to schedule their day, keep them focused and how to respond to their behaviour challenges.

Bjørn Christensen

Regional Service Manager, Community Connections, New Zealand

My name is Bjørn Christensen and I am very excited to be a part of this year's conference in Berlin. I work for an organisation called Community Connections and I have spent the last four and a half years managing a service for an amazing woman named Francie, who lives here in Wellington, New Zealand. There are many complexities and nuances involved in providing a successful service for someone living with Prader Willi syndrome. With Aotearoa (New Zealand) being a smaller nation, we are in some ways isolated with information sharing when it comes to best practice. I am very proud of the work that I have been able to do alongside Francie but I am always seeking ways to improve. It is my hope from this conference that I will be able to establish connections, learn new strategies and come away with a greater understanding of what other communities are doing around the world to provide safe, happy and exceptional support for those with Prader-Willi. I also want to bring this knowledge home to Wellington and share this with our team.

Saoirse Kavanagh

Trinity College Dublin, Ireland

Saoirse is an Assistant Psychologist from Dublin, Ireland who completed a Bachelor's Degree in Psychology at Maynooth University and went on to complete a Masters in Applied Psychology at Trinity College Dublin. During her studies, Saoirse collaborated with the Prader-Willi Syndrome Association Ireland and carried out 2 research projects investigating the well-being of siblings of individuals with Prader-Willi syndrome, shedding light on their individual experiences.

Being selected as a recipient of this grant is a tremendous honor for me. It acknowledges my commitment and contributions to the field of Prader-Willi syndrome research and caregiving. As a travel grant recipient, I have the invaluable opportunity to attend the conference, engage with leading experts, participate in discussions, and network with peers from around the world. This experience will not only enhance my knowledge and understanding of the condition but also enable me to exchange ideas, collaborate on initiatives, and ultimately make meaningful contributions toward improving the lives of individuals affected by Prader-Willi syndrome.

Van Dinh Thi Thanh

Psychologist, Morning Star Institute, Vietnam

I am Van, a psychologist from Vietnam. I have been working for 7 years in a clinic at Morning Star Center, a center for children with intellectual disabilities in Vietnam and I provide assessment for children with intellectual disabilities, including children with PWS and provide consultancy to their families.

I hope to improve my knowledge about PWS and update new methods of intervention for people with PWS as well as meet and learn more from care-givers and professionals who support people with PWS around the world.

Dr. Paula Arce Sanz

Dietician Nutritionist, Asociación Colombiana Síndrome de Prader-Willi, Colombia

Paula Arce Sanz is Medical Director of the Colombian SPW Association and a Dietitian Nutritionist from the Catholic University of Manizales. She has a diploma in Pediatric Clinical Nutrition at the Favarolo University in Buenos Aires (Argentina) and at the Javeriana University (Colombia). Master in Pediatric Clinical Nutrition at the University of Granada (Spain). 14 years of experience in Maternal and Child care. Certified in Pediatric Nutritional Support. Certified in Pediatric Nutritional Support. Benutrition Cali Manager.

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