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# 2019 Annual Report

**IPWSO**  
INTERNATIONAL  
PRADER-WILLI SYNDROME  
ORGANISATION





# IPWSO Annual Report 2019

## Our vision

A world where people with PWS have access to information, treatment and quality services and are integrated into their communities.

## Our mission

IPWSO's goal is to improve the physical and mental well-being, socially as well as occupationally, of all people with Prader-Willi syndrome (PWS), so that they may, according to their ability, lead a life as normal as possible and be in a position to achieve their full potential as allowed by the constitution of their country, and what is set out in the UN Convention on the Rights of Persons with Disabilities.

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# President's report: Tony Holland reflects on a productive 2019



The last 12 months have been significant in two major but very different ways. First, we held the 10th International Prader-Willi Syndrome Organisation conference in Havana, Cuba, in partnership with the Cuban Society for Human Genetics. Secondly, we completed our registration to become a Charitable Incorporated Organisation (CIO) with the Charity Commission of England and Wales.

Although our work in 2019 was dominated by preparations for the Cuba conference we also continued our other activities as described later in this report. I am very grateful to the Clinical and Scientific Advisory Board (CSAB), chaired by Dan Driscoll, the Professional Providers and Caregivers Board (PPCB), chaired by Norbert Hödebeck-Stuntebeck, and Famcare, chaired in 2019 by Georgina Loughnan and now in 2020 by Verena Gutmann, for their immense support in organising the conference and their ongoing work preparing guidance and in responding to the many queries we receive.

My thanks also goes to Amalia Balart and Mariona Nadal from IPWSO and to Beatriz Marcheco Teruel, Yaíma Zúñiga Rosales and many others from the Cuban Society for Human Genetics for their contribution to the organisation and running of the conference. The conference would not have been possible without the expertise and hard work of Agnes Hctor and Marguerite Hughes.

In the lead up to the conference the Board had concerns about what were increasing restrictions on travel from the USA to Cuba and also stories we heard of shortages and hardship there. However, our decision to continue was well rewarded by an attendance of 480 delegates, from a total of 43 countries. Our Cuban hosts had worked very hard to ensure that the conference ran smoothly and the atmosphere throughout the different parts of the conference was very special. Further details about the Cuba conference are covered elsewhere in this document.

Highlights of our work this year included translating many of our factsheets into Spanish and some into Portuguese in preparation for IPWSO's first major conference in the Spanish speaking world. In addition, we provided financial and practical support to workshops in Vietnam and Colombia, and Susanne Blichfeldt contributed on our behalf to similar events in Romania and Bulgaria.

IPWSO was represented at the meetings of the European Society for Paediatric Endocrinology, European Congress of Endocrinology and the International Association for the Scientific Study of Intellectual and Developmental Disabilities. We have also continued to fund and facilitate genetic testing for people who cannot access such testing in their own country.



# President's report...



*The IPWSO and SOCUGEN conference organising team*

At the end of the Cuba conference we held our General Assembly meeting. The key task was to choose the venue for our next international conference. My thanks to India, Ireland, Malaysia and Thailand who put themselves forward - all could well have been chosen. My congratulations to the winners, the Republic of Ireland. The conference will take place from 6th to 10th July 2022 at the University of Limerick campus on the west coast of Ireland.

The General Assembly is also the time to say goodbye to Board members and to welcome new ones. June-Anne Gold, Marguerite Hughes, Georgina Loughnan, Mariona Nadal and Hubert Soyer all left the Board and François Besnier, Lynn Garrick, Maria Libura, Craig Moore, Marcello Schutzer and Kate Woodcock were elected to replace them. My immense thanks to those who are leaving and a welcome to those who are joining, we are delighted that Marilyn Dumont-Driscoll, has agreed to stay on as a co-opted member. We also said goodbye to Linda Thornton who has provided wonderful organisational support to IPWSO for many years.

At the time of the annual report being published every country in the world is struggling with the COVID-19 pandemic. This is, and will continue to be, a challenging time for all of us not least people with PWS and their families and also for small charities, such as IPWSO. We have tried to respond by ensuring that information on COVID-19 and how it might impact on people with PWS is provided on our website. The CSAB and PPCB have together launched a large survey so that we can better understand how a viral illness, such as COVID-19, might affect people with PWS.

We value your support in all that IPWSO does. To help us we now have Marguerite Hughes as our Chief Executive Officer, Agnes Hughes as our Communication and Membership Manager and Luke Ablard as Website and Conference Manager. We have new initiatives planned for 2020. Please continue with your support and let us know what more we can do to help you.

# Chief Executive Officer's report: Marguerite Hughes looks forward into 2020



At the time of writing, COVID-19 is making its presence felt around the world. We in IPWSO recognise the anxiety and challenges that this is causing people with PWS and their families. We recognise too the heightened pressure and responsibility that it has placed on the shoulders of the many doctors, other health professionals, and professional caregivers who serve as volunteers on IPWSO's boards and committees.

Although we don't know when the pandemic will end, or how it may change our world, we do know that people with PWS and their families will continue to need and deserve support long after the pandemic is over.

So, even in these most difficult times, we continue to plan new initiatives and supports while simultaneously endeavouring to maintain our existing services. We have been particularly encouraged during this time by an extremely generous donation from IPWSO's first President, Jean Phillips-Martinsson. This has enabled IPWSO to establish the Jean Phillips-Martinsson Fund in honour of Jean's late husband, Sven, and her late son, Anders. These funds allow IPWSO both to continue its core activities and to expand its work.

We have already initiated a trial Project ECHO® telementoring program that is bringing together leaders from PWS associations around the world in a series of online training sessions. We have been delighted with the positive feedback of the participants and we hope to initiate additional Project ECHO® groups later in 2020.

Although deferred until 2021, we plan to support several national and regional PWS conferences as soon as it is safe to do so. We plan to directly share information about PWS by hosting information booths at medical conferences. We also plan to consider ways in which IPWSO can influence the development of national and international policies that impact on people with PWS and their families.

Again in 2020 IPWSO is providing free diagnostic testing services for people who cannot access this in their own countries. Again IPWSO will respond to queries from the public and our boards will continue to work on research and publications that will assist the global PWS community. We plan also to revamp our website to make it easier for people to find the information we provide online.

While COVID-19 has resulted in a difficult start to 2020, we are determined to continue to fulfil our mission to improve the lives of people with PWS and their families around the world. I am honoured, as IPWSO's newly-appointed CEO, to play a part in this work.



# Treasurer's report:

## Marcello Schutzer



First of all, I want to mention that I am honoured with the privilege of joining the Board of IPWSO, formed by high caliber professionals, motivated by a shared purpose of improving the quality of life for all people with Prader-Willi syndrome and their families.

IPWSO was incorporated in England and Wales as a Charitable Incorporated Organisation (CIO) on April 9th, 2019. IPWSO's members voted at EGMs held in October 2019 to transfer all funds, other assets and operations of the original unincorporated IPWSO to IPWSO-CIO and to dissolve the unincorporated IPWSO once these transfers had been completed. Because of the above, there are two separate financial reports for 2019. The first reflects those of the unincorporated IPWSO until dissolution. The second reflects those of IPWSO-CIO from its incorporation on April 9th, 2019 to the year end.

Thank you to those of you who have supported us financially. We thank all of IPWSO's members who paid subscription fees during 2019 and particular thanks to those who also contributed additional voluntary donations.

Thanks to all the sponsors of the 10th IPWSO Conference, especially the Platinum sponsors, Pfizer and Millendo Therapeutics, and the Gold sponsors, Zafgen and Levo Therapeutics.

I want to thank Soleno Therapeutics for sponsoring IPWSO's Diagnostic Testing Service and a booth at the European Society of Paediatric Endocrinology Conference. I also want to thank Friends of IPWSO (USA) for supporting multiple projects, including conferences in Vietnam and Colombia, the translation of educational materials into Spanish and Portuguese, educational booths at medical conferences, and the sponsorship of 11 outstanding candidates to attend the 10th IPWSO conference in Cuba.

Finally, I want to extend a special thank you to Tony Holland and Marguerite Hughes for their passion and commitment to make IPWSO such a great charity organisation.

# Financial report: Unincorporated IPWSO

During the period of our existence as an unincorporated entity, IPWSO maintained two accounts, one in Euros and one in US Dollars. In the Euros account, we started the year with a balance of €60,242.80, and raised €52,963.54 through a combination of sponsorships for the conference in Cuba, donations and membership fees. From these funds, we allocated €38,244.44 mainly in staff salaries, organisation of the conference in Cuba, support to other conferences and BIRD diagnostic tests. This left a balance of €74,961.90 that was transferred to the new IPWSO account in the UK, as detailed below:

<b>Euros Account</b>		
<b>Beginning Balance</b>	<b>60,242.80</b>	A
Sponsorship/donations for Cuba	39,441.29	
Membership fees	7,912.50	
Donations	5,609.75	
<b>Total Income</b>	<b>52,963.54</b>	B
Staff salaries	13,700.00	
Conference expenditures	11,223.28	
BIRD tests	5,400.00	
Cuba conference - expenditures and travel grants	5,322.43	
Bank charges	690.37	
Office expenses / others	1,908.36	
<b>Total Expenditures</b>	<b>38,244.44</b>	C
<b>Transfer to IPWSO Account in the UK</b>	<b>74,961.90</b>	A+B-C

In the Dollars account, we started the year with a balance of US\$94,178.65, raised a total of US\$11,414.47 from sponsorships and donations for the conference in Cuba, and generated US\$1,435.65 in interest income. From these funds, we allocated US\$33,728.36 mainly with the organisation of the conference in Cuba, support to other conferences, expenses related to registration as a charity in the UK and translations. This left a balance of US\$73,300.41 that was transferred to the new IPWSO account in the UK, as detailed below:

<b>US\$ Account</b>		
<b>Beginning Balance</b>	<b>94,178.65</b>	A
Sponsorship/donations for Cuba	11,414.47	
Interest income	1,435.65	
<b>Total Income</b>	<b>12,850.12</b>	B
Cuba conference - expenditures and travel grants	14,143.19	
Conference expenditures	10,097.77	
Charity registration in the UK	5,604.20	
Translations	2,484.39	
Bank charges and others	1,398.81	
<b>Total Expenditures</b>	<b>33,728.36</b>	C
<b>Transfer to IPWSO Account in the UK</b>	<b>73,300.41</b>	A+B-C

## Auditors' Note

The Auditors have reviewed the above Treasurer's report and have concluded that it correctly represents the financial position of the unincorporated IPWSO in 2019.

Gerard Meijwaad, The Netherlands & Jim Gardner, USA



# Financial report: Charitable Incorporated Organisation IPWSO

## Financial Review and Reserves Policy

The transfers of €74,961.90 and US\$73,300.41 from the two bank accounts of the unincorporated IPWSO built a beginning balance of £122,490 in the incorporated IPWSO accounts.

This was compounded by additional donations from Foundations (£25,105), Corporate (£2,389) and other smaller sources of income such as subscriptions and donations (£1,363). All combined, total receipts at incorporated IPWSO in 2019 were £151,347.

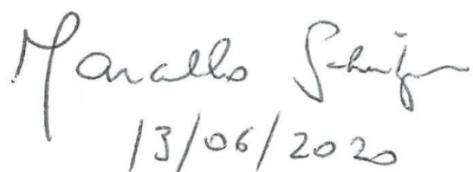
These funds were mainly invested in the following: 10th IPWSO conference (£19,016); staff salaries (£4,823); travel scholarships (£2,827); and other various expenses such as office costs, insurance, bank charges, 11th IPWSO conference preparations and accountancy fees (£2,328). Total costs incurred by incorporated IPWSO in 2019 were £28,994.

As a result, the net balance of receipts minus costs in 2019 was £122,353. This is exactly the same amount held in the bank accounts on December 31st, 2019.

The Trustees are satisfied that the level of free cash funds, currently £122,353, is adequate to meet the objects of the CIO. The Trustees decided that a reserve of US\$100,000 (as at 31 December 2019: £76,254) should be aimed for.

**An Independent Examiner's Report has been carried out on the accounts of the Charitable Incorporated Organisation by Mrs J Coplowe FCA, for and on behalf of Peters, Elworthy and Moore, Chartered Accountants, Cambridge, UK.**

**The financial statements of both the Unincorporated and Charitable Incorporated Organisation IPWSO were approved by the Board of Trustees on 13th June 2020 and signed below on its behalf by our Treasurer:**



13/06/2020

Treasurer, 13th June 2020

# Financial report: Charitable Incorporated Organisation IPWSO

## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION Receipts and Payments Account for the period ended 31 December 2019

	2019 Restricted	2019 Unrestricted	2019 Total
	£	£	£
<b>Receipts</b>			
Donations - Corporate	-	2,389	2,389
Donations - Foundations	1,634	23,471	25,105
Subscriptions	-	446	446
Other Fundraising and Donations	-	917	917
Founding donations	-	122,490	122,490
<b>Total receipts for period</b>	<u>1,634</u>	<u>149,713</u>	<u>151,347</u>
<b>Payments</b>			
10 <sup>th</sup> IPWSO conference costs	-	19,016	19,016
11 <sup>th</sup> IPWSO conference costs	-	40	40
Office costs	-	220	220
Insurance	-	188	188
Website development costs	-	22	22
Salaries	-	4,823	4,823
Pension costs	-	91	91
Travel scholarships	-	2,827	2,827
Bank charges	-	460	460
Accountancy fees	-	59	59
Foreign exchange	-	1,248	1,248
<b>Total payments for period</b>	<u>-</u>	<u>28,994</u>	<u>28,994</u>
Net receipts being net movement in funds	1,634	120,719	122,353
Cash funds brought forward	-	-	-
<b>Cash funds at the period end</b>	<u>1,634</u>	<u>120,719</u>	<u>122,353</u>

## INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION Statement of Assets and Liabilities 31 December 2019

	2019 Restricted	2019 Unrestricted	2019 Total
	£	£	£
<b>Monetary Assets</b>			
HSBC GBP	1,634	48,722	50,356
HSBC EUR	-	56,383	56,383
HSBC USD	-	15,614	15,614
<b>Cash funds at end of the period: Total Monetary Assets</b>	<u>1,634</u>	<u>120,719</u>	<u>122,353</u>
<b>Liabilities</b>			
Independent Examination & Accountancy fee for 2019	-	2,160	2,160
Bookkeeping fee	-	150	150
PAYE Payable	-	186	186
Pensions Payable	-	68	68
<b>Total Liabilities</b>	<u>-</u>	<u>2,564</u>	<u>2,564</u>



# Clinical and Scientific Advisory Board: Dan Driscoll



## **Scientific papers**

The CSAB has continued to prepare pdf files listing scientific papers published over the previous three-month period in peer reviewed journals. These lists have been circulated widely at the international level by the IPWSO office. The range of research being published is extensive and includes basic science and a broad range of clinical topics from genetics, to endocrinology, and to behaviour and mental health. There are papers reporting on clinical trials of specific interventions and the application of some of the advanced neuroimaging techniques. A special note of thanks should go out to Joyce Whittington for her help in preparing this material.

The quarterly collection of papers is available on our website: [www.ipwso.org/research-papers](http://www.ipwso.org/research-papers)

## **Advice**

The CSAB developed a standardised form for queries. During this past year members of the CSAB have responded to requests for advice on a number of topics.

The CSAB put together Medical Overviews and Checklists documents for Infants, Children, Adolescents, and Adults with PWS for families and health care professionals around the world. These documents are freely available on the IPWSO website in English and Spanish. They have been well received and were presented at the IPWSO meeting in Cuba in November 2019 and at the Prader-Willi Syndrome Association (USA) meeting in Orlando, Florida in October 2019.

## **Advocacy**

The CSAB wrote and had published a Letter to the Editor of the Clinical Endocrinology medical journal advocating for the use of growth hormone therapy in adults with PWS.

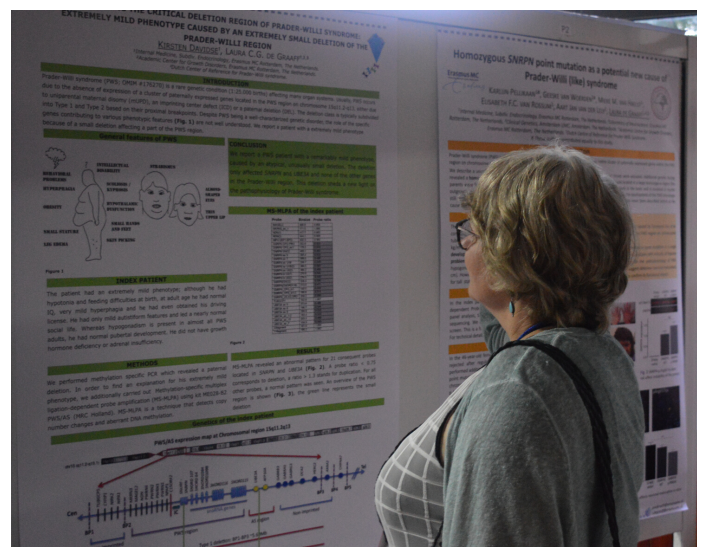
## **IPWSO meeting in Havana, Cuba November 2019**

The CSAB organised a half day workshop on “Sexuality in PWS”, as well as the two day Clinical and Scientific meeting which was well attended by clinicians and scientists from around the world.

# Clinical and Scientific Advisory Board...



*The Clinical and Scientific Advisory Board meeting in Cuba*



*The Scientific and Clinical meeting received almost 100 abstracts*

# Famcare - Family Care Board: Georgina Loughnan



We have had a productive year, producing five new articles, updating one of our earlier papers and producing a record number of translated factsheets.

## Our new articles:

- *When Rituals Become a Problem* addresses issues around repetitive or ritualistic behaviour. What may begin as an interest in something or an ordered way of doing things can become an entrenched habit or obsession. Extended times to complete a task, excessive use of hygiene products and collecting or hoarding of certain items can cause much concern for people with PWS and their families.
- *Transitional Years* discusses the importance of planning for the significant periods of change in a person's life and how transitional planning can help a person with PWS.
- *Life Plan* is an adaption of work produced by Kate Beaver, a member of Famcare highly experienced in education and counselling of children and adolescents with PWS. The Life Plan is to be completed by a trusted family member or carer, with and for the person with PWS. It is a place to collate information about the person with PWS, which is relevant to the people in their lives who care for them or assist with their lifestyle management.
- *Law Enforcement Matters* is a snapshot of PWS for families or carers to give to anyone from law enforcement agencies, who may become involved with someone who has PWS, as a result of difficult behaviour. It is to assist the law enforcement personnel in their understanding of antisocial or unlawful behaviour that may be seen in people.
- The final article completed for 2019 is *Motivation*. If we could only package motivation for sale, we would all be millionaires! To motivate someone with PWS we must focus on understanding PWS, on what builds self-esteem and the wants of people with PWS.

The article *PWS Awareness for Professionals* was updated last year and has proven to be a most useful tool for families across the globe. The Famcare articles are now included in material that is distributed at IPWSO awareness events, conferences and workshops.

Linda Thornton continued to work this year towards increasing the number of Famcare articles that are translated in languages other than English. We now have Arabic, Dutch, German, Italian, Hindi, Mandarin, Russian and Spanish translations of several Famcare articles with more to be translated each year. If anyone in the PWS community can assist with translations we would be most grateful!



# Famcare...

We were delighted to organise the Parents' programme at the Cuba conference this year and to see so many families, old friends and new, come together to learn from each other.



This will be my final year in the privileged role of a member of the IPWSO Board. I have thoroughly enjoyed my time on the Board and all it has involved. When I was asked by Susie Cassidy, who needs no introduction, to initiate the group that is now known as Famcare, it was a challenge! What a joy it has been to coordinate the experiences and expertise of the parents and professionals involved in Famcare!

Thank you to all involved for the personal and professional knowledge, expertise and friendship you have shared. I now pass on the coordination of Famcare to my colleague Verena Gutmann.

There is no greater joy than working with like-minded people, and more importantly like-hearted people, who are doing what they do for the betterment of others. Wishing you all the very best for the future.

# Professional Providers and Caregivers Board: Norbert Hödebeck-Stuntebeck



2019 was another intensive and successful year of work for the PPCB. The development of the Caregivers conference as a part of the IPWSO conference in Cuba was the main focus of work this year. To build the program, find the speakers and run the conference over two days was a big project and happily very successful.

More than 130 people from over 20 different countries from all over the world participated and discussed the themes around overviews of services in different countries, actual problematic themes in PWS and visions of the future for the care of people with PWS.



To be able to handle events like the conference in Cuba it is necessary to have a competent team of engaged people. In 2019 we are very happy to find two new PPCB board members. Laura Keane joined us from Ireland, with her main competences in delivering supports which empower and enable people with disabilities. Neil Gumley joined us from Australia. His expertise is focused on establishing new residential facilities for people with PWS in Australia.

In 2019 three of our (founder) members: Fanny Cortes from Chile, Lisa Boman from Sweden and John Ford from New Zealand stepped down from PPCB because their regular jobs needed their undivided time. Michael Pethe also stood down at the end of the year due to other commitments. In the name of PPCB and IPWSO we are very, very thankful for you Fanny, Lisa, John and Michael for your enthusiastic and engaged work for the PPCB and IPWSO.



# Professional Providers and Caregivers Board...

If we take a look at the future it shows what the main themes and tasks for PPCB will be and where we want to go:

- Continuing the planning of separate caregivers conferences (the next in Berlin running from 31st August to 2nd September 2021) and also to start developing first ideas for the IPWSO conference in Ireland in 2022.
- Working on the development of continuous offers of PWS summer camps in different parts of the world.
- Working on the development of standards in the care of people with PWS.
- Working with and coordinating IPWSO caregiver delegates as multipliers of knowledge in their countries.
- Cooperation with all parts of the big IPWSO family.

These big tasks we can only realise as a strong team and there for I am very thankful to the PPCB members: Mary K. Ziccardi, Jackie Malow, Laura Keane, Hubert Soyer, Larry Genstil, Damien Jones, Neil Gumley, Patrice Carroll and Norbert Hödebeck-Stuntebeck.

All the best and let's go on.



# Our 10th international conference: Havana, Cuba

We host an international conference every three years, it is the biggest event in our calendar and a powerful opportunity to strengthen the links between members of the international Prader-Willi syndrome family.

Our most recent conference was held over five days in November 2019 in Havana, Cuba in partnership with the Cuban Society for Human Genetics (SOCUGEN). Whilst we were delighted to bring our conference to Latin-America for the first time, the event, which was the first which IPWSO has been heavily involved in organising, was a big challenge in terms of navigating an unusual and unfamiliar host nation. Despite the difficulties in the run up to the event and some problem-solving on arrival at the venue, we had one of our most successful conferences to date.

The conference was attended by over 480 delegates from 43 countries (including 200 people from Cuba) who came together to share their knowledge and experiences across the three conference strands plus the activities for People with PWS. Our local hosts from SOCUGEN and volunteers from CARITAS were extremely welcoming and responsive to our needs and the enthusiasm and commitment of the Cuban professionals and families was wonderful to see.



We were delighted to be able offer simultaneous translation into Spanish for much of the conference, a first for us which was very well received.

Highlights of the week included a really strong Scientific programme. We were delighted by the standard of the academic abstracts and presentations with almost 100 abstracts received which helped build a robust programme and poster display.

# Our 10th international conference...

There was also huge interest in the Caregivers' programme with fascinating presentations from around the world demonstrating different models of how care homes operate.

The Parents' conference concluded the event on the Saturday and Sunday of the conference and as always was extremely collaborative with many professionals from the Scientific and Carers' conferences staying on to speak and take part.

We attracted the interest of BBC reporter Will Grant whose team filmed and conducted interviews during the week. Our President Tony Holland was interviewed by the BBC along with Loisel Bello, one of our key Cuban organisers and some of the Cuban families. Will's report was broadcast on TV and radio on 26th December along with an online report.



Thanks to funding from the Friends of IPWSO (USA) we were able to offer financial assistance to 11 exceptional delegates to attend the Cuba conference. Many people applied for this funding and we were sorry not to be able to support more of them. The delegates came from countries around the world including Georgia, Mexico, Bulgaria and India and also came from diverse backgrounds including professionals and families.

Amongst the travel scholars was Esther Maina PhD who travelled to Cuba from Kenya. Esther has been concerned about the lack of PWS diagnosis in the East African region and has been working with paediatricians in Kenya to find out more about the true reality for children with PWS in the area.

Esther told us, "Attending the 10th IPWSO conference was most enriching for me personally and as a scientist... The sessions enabled me to foster discussion and strengthen connections between myself and my proposed research work and the other participants, with the aim of establishing a support group for the parents and care givers back in Kenya."



# Our 10th international conference...



This conference was our first to be held in the Spanish speaking world and our Board member Amalia Balart brought together the Latin American delegates for a really productive and exciting meeting on the Friday of the conference. We hope this group will continue to flourish.

The conference ended in the traditional way with our General Assembly and the vote to choose our next conference location. We were delighted to receive strong bids from India, Ireland, Malaysia and Thailand. Ireland was voted in first place and we are already working with the team from the Prader-Willi Syndrome Association Ireland to plan for our 11th international conference.

**The 11th International Prader-Willi Syndrome Organisation Conference will be held at the University of Limerick campus in Ireland from 6th to 10th July 2022.**

# Projects

## Translations

In 2019 we undertook a major piece of work to translate many of our factsheets into other languages with a particular focus on Spanish. This work was supported by Friends of IPWSO (USA). We were also supported by several of our member associations who undertook the translation of several documents including PWSA Japan amongst others.

## Conferences and workshops:

### Colombia, March 2019

In 2019 IPWSO and Friends of IPWSO (USA) gave financial support to the development of a conference held in Bogotá to discuss behavioural and metabolic disorders. Organised by the Colombian Prader-Willi Syndrome Association in partnership with other local bodies, the event was attended by 500 delegates from Colombia, Chile, Guatemala, Panama and the USA and attracted international speakers from the USA, Spain and Chile as well as speakers from a wide range of professional backgrounds from Colombia.

Delegates came from the health, education and rehabilitation sectors and many associated professions. The conference helped the Colombian association to reach new families as well as professionals who will now work with them to support their activities.



# Projects

## **Bulgaria, March 2019**

IPWSO expert Dr Susanne Blichfeldt was contacted by Dr Nikolinka Yordanova from Bulgaria, regarding a visit to Varna to attend a conference of families and professionals. We had already received some questions about two children with PWS there and were interested to follow this up. With the support of IPWSO, Susanne attended the meeting and played a major role in the event.

Dr Blichfeldt was asked to give presentations with a focus on food and nutrition and neurology for an audience consisting of parents and professionals. Parents of children with PWS were also invited for an afternoon session and individual consultations with some of the families were facilitated. For many parents it was the first time they had met other families affected by PWS

It is now possible to perform genetic testing for PWS in Bulgaria, all children can have growth hormone for free, but sleep studies are difficult to perform. Children are offered special education in school, and many have physiotherapy, the youngest in some cases have this every day, and for free. For adults with PWS the situation is difficult. There are no PWS homes, so most people stay at home with their parents. Some people can go to day centres with other people with disabilities, but a big problem is that there is little or no support for the control of food. Management of difficult behaviour, also related to food, is a problem.

In Varna, the hospital for children is also a centre for rare diseases and endocrinological problems and Professor Iotova and Dr Yordanova have developed a specialism in PWS. They inform other doctors in the hospital, have translated many articles from the IPWSO website into Bulgarian and they try to communicate about PWS to other hospitals in Bulgaria.

## **Vietnam, October 2019**

Georgina Loughnan (Board member), Constanze Lämmer (paediatrician and nutritionist) and Norbert Hödebeck-Stuntebeck (Chair of our Professional Providers and Caregivers Board) visited Hanoi, Vietnam, to present a Prader-Willi syndrome programme at the request of Do Thuy Lan, a psychiatrist who established the Morning Star Centre for children with disabilities and who won a scholarship to attend our Caregivers conference in Munich in 2018.

The first day was attended by about 80 professionals, including a paediatric endocrinologist and a geneticist, and many of the Morning Sun staff. The second day was attended by about 36 parents and 30 Morning Star staff members. We met with Dang Trung Tam, the president of the PWS Vietnam Network or “club” and many keen parents. Lantz Yap, from the Malaysian PWS Association joined the Sunday programme. The Vietnamese PWS Network includes 60 families. All children known to the network are under 16 years of age.

# Projects

The content of the two days focused on physical, social, cognitive and emotional characteristics of PWS. This was the basis for the more individual and specific questions and answers from professionals and parents. Afterwards the participants felt very well informed and reported they had a better perspective on the future care of their children and the professionals who worked with them.

The situation in Vietnam for people with PWS needs development. Children may attend a facility, such as the Morning Star if their parents can afford the costs, but otherwise stay at home. There are no “special needs” schools in Vietnam. Lan reported that The Morning Star costs are much lower than most centres in Vietnam, and she adjusts the fees for those who are very poor. She receives no government funding, but her son-in-law has encouraged a group of his friends to sponsor some of the children to attend.

The children receive the therapies they require and life-skills training, such as dressing themselves and housework such as making the bed and cooking. The training rooms are small and closed in, but the children receive a high ratio of staff support, including one-to-one for sensory and speech therapy. Growth Hormone is available in Vietnam but at a cost for the families.

## **Romania, November 2019**

In November, Dr. Susanne Blichfeldt travelled to Bucharest on behalf of IPWSO to speak to families at a conference organised there. She presented on nutrition, development, neurology and behaviour and general medical issues. She also conducted several 30-minute sessions one-to-one with family groups, sharing her knowledge and experience.

# Projects

## Exhibition stands

Hosting educational booths at medical conferences has long been a means by which we have sought to raise awareness of Prader-Willi syndrome and the services we provide. Our participation in the exhibitions at three external conferences in 2019 once again reminded us why such booths continue to be important.

**The European Congress of Endocrinology** meeting was held in Lyon, France in May, and attended by over 4,000 endocrine specialists. Mariona Nadal hosted our booth and around 300 IPWSO memory sticks were distributed, along with our leaflets and materials provided by the French PWS association. In total around 350-400 people visited the booth. Visitors came from all around the world. The IPWSO booth remained open for 4 days and Mariona was assisted by four volunteers from the French association who paid all their own costs to attend.

The international meeting of the **International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)** was held in Glasgow, Scotland, in August. This was attended by approximately 1,200 people from over 40 countries. We had a stand in the main hall and through the 5 days there was a steady stream of visitors. Approximately 150 memory sticks were distributed along with brochures and information on the IPWSO meeting in Cuba. The majority of those visiting our stall were support staff or health workers who knew or were supporting someone with PWS. In addition to manning the stand, Tony Holland was invited to give a key note talk much of which was devoted to how research has informed our understanding of the behaviour problems experienced by people with PWS.

In September we attended the **European Society of Paediatric Endocrinology (ESPE) Conference** in Vienna, Austria. Over the course of 3 days, 370 flash drives containing information about PWS in a variety of languages were collected from the booth. 168 delegates from 54 countries signed up to our mailing list. The issues raised by the steady stream of visitors to the booth provided a useful insight into the current concerns of endocrinologists who treat people with PWS. Securing Growth Hormone Treatment for adults with PWS was by far the most commonly-raised challenge. Questions about clinical trials and the prospect of new treatments were also frequent. So too were questions about challenging behaviour.



# Projects

## **Project ECHO®**

We have been working through 2019 to establish an IPWSO Membership Project ECHO® (Extension of Community Healthcare Outcomes). Our plan is to expand our international reach into countries where family support is desperately needed, using technology enabled telementoring.

In 2020 we plan to launch our first telementoring initiative to foster the establishment and growth of national PWS associations. We will set up technology enabled communities of practice to enable knowledge to be decentralised from the minds of experts in developed countries to emerging family support organisations leaders in the countries where they live. Technology based 'all teach, all learn' hub and spoke mentoring will facilitate the transferring of strategic and organisational expertise and knowledge leading to organisational capacity building. This process will expand the reach and confidence of new and emerging national family support communities, to provide the localised support for people with PWS and their families where it is needed most.

This is an exciting new venture for us which is being spearheaded by our Vice President James O'Brien.

## **Diagnostic testing at the Baschirotto Institute for Rare Disorders (BIRD)**

For the 17th consecutive year IPWSO offered free diagnostic testing for PWS to those who are unable to access testing in their own countries. This service was provided in collaboration with the Baschirotto Institute for Rare Diseases (BIRD), which is based in Vicenza, Italy.

In 2019, tests were conducted on 18 samples received from doctors in Brazil, Bulgaria, Georgia, India, Peru and Uruguay.

All diagnostic tests conducted on behalf of IPWSO in 2019 were paid for through a generous grant from Soleno Therapeutics.

Since the inception of its free diagnostic testing service, IPWSO has funded testing for over 500 families around the world.

# About us

IPWSO is a membership body for the national associations working in the field of Prader-Willi syndrome around the world. In 2019 we had 34 paid country members and 74 associate country members. We are a charity registered in England and Wales, number 1182873.

We have a working board of 10 trustees, the Board changed at the international meeting in November.

## Our Trustees: 2016 to 2019

Tony Holland, President  
Marguerite Hughes, Vice President  
Amalia Balart  
Marilyn Dumont-Driscoll  
June-Anne Gold  
Verena Gutmann  
Georgina Loughnan  
Mariona Nadal  
James O'Brien  
Hubert Soyer

## Our Trustees: 2019 to 2022 (pictured)

Tony Holland, President  
James O'Brien, Vice President  
Amalia Balart  
François Besnier  
Lynn Garrick  
Verena Gutmann  
Maria Libura  
Craig Moore  
Marcello Schutzer  
Kate Woodcock  
Co-opted: Marilyn Dumont-Driscoll



## Our staff

Marguerite Hughes, Chief Executive Officer  
Agnes Hctor, Communication and Membership Manager  
Luke Ablard, Website and Conference Manager

# About us

## **Clinical and Scientific Advisory Board**

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Janice Forster, USA  
Jackie Gill, UK  
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Hubert Soyer, Germany

## **Our advisers**

Dan Beaver, USA  
Suzanne Cassidy, USA  
Peter Davies, Australia  
Nick Finer, UK  
Joan Gardner, USA  
Jackie Gill, UK  
Barbara J Goff, USA  
Tony Goldstone, UK  
David Gordon, USA  
Janalee Heinemann, USA  
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Tomoko Iwasaki, Japan  
Constanze Lämmer, Austria  
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## **What is Prader-Willi syndrome?**

Prader-Willi syndrome is a complex genetic disorder that is usually not hereditary. It can occur in any family and, in most cases, only one child will have it. It is not an illness and there is no cure. It is typically characterised by low muscle tone, short stature (when not treated with growth hormone), incomplete sexual development, disturbed sleep patterns, cognitive disabilities, behavioural problems, and a chronic feeling of insatiable hunger that can lead to excessive eating and life-threatening obesity.

Different researchers have estimated that between 1 in 12,000 and 1 in 22,000 people is born with Prader-Willi syndrome. Prader-Willi syndrome is found in people of both sexes and in all races.

## **Support IPWSO**

- To donate please visit us at [www.ipwso.org](http://www.ipwso.org)
- Join our mailing list through our website
- Follow us on Facebook, Twitter, Instagram and LinkedIn
- Attend our next conference in Ireland, 6-10 July 2022

IPWSO is registered as a charity in England and Wales, charity no. 1182873.