



IPWSO

International
Prader-Willi Syndrome
Organisation

ANNUAL REPORT



WWW.IPWSO.ORG

REGISTERED AS A CHARITY IN ENGLAND & WALES
NUMBER 1182873

Our Vision

A world where people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

Our Mission

To unite the global PWS community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS associations, and professionals who work with people with PWS.

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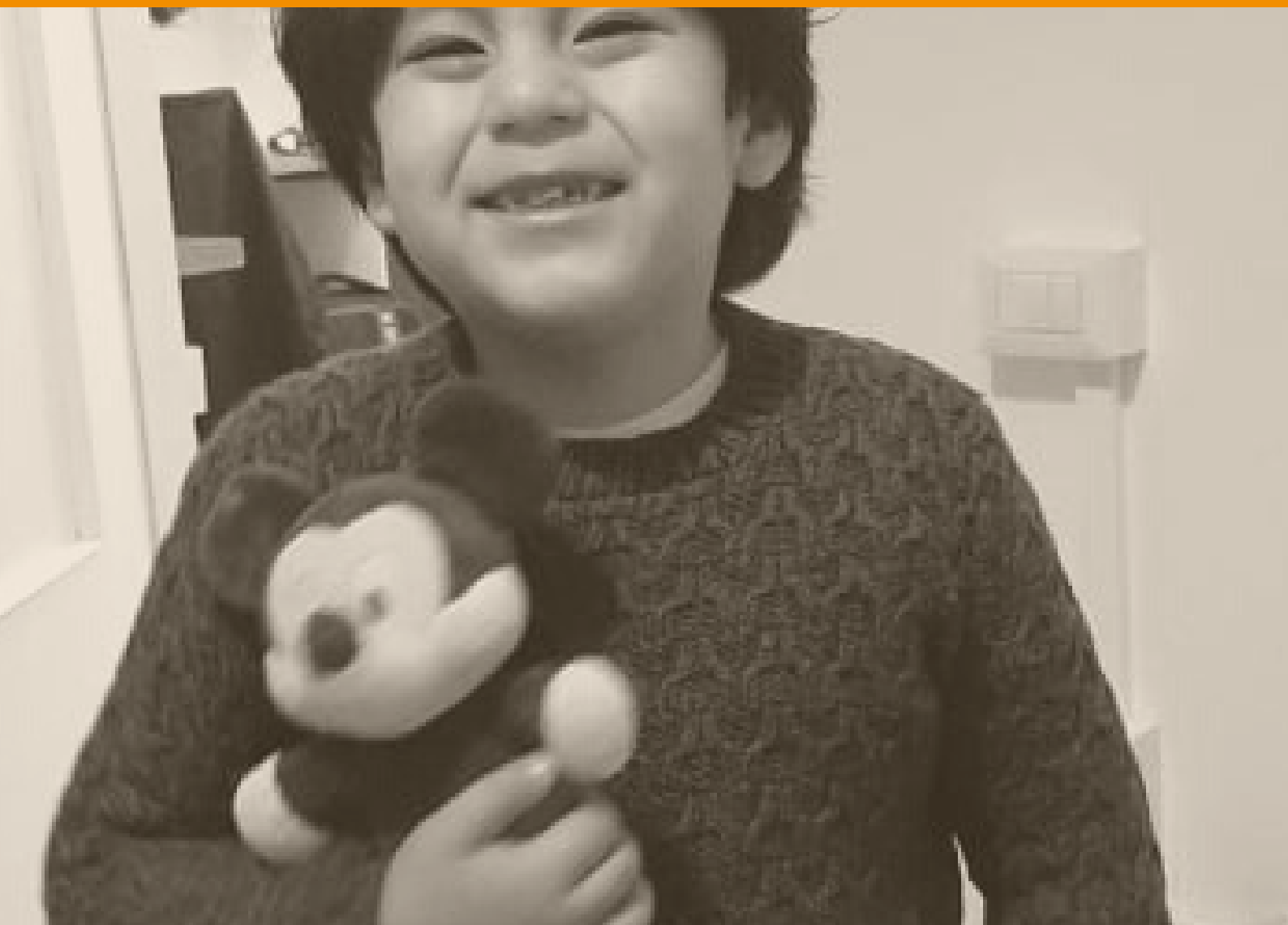
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ANNUAL REPORT 2020



WELCOME



President's report

Professor Tony Holland, 2020: A year like no other

None of us could have imagined at the beginning of 2020 what life would be like just a few months later. COVID-19 has determined how we live, whom we see, and what we do. For people with PWS and their families and those providing support, restrictions were imposed and routines changed, exercise was more difficult but life had to go on.

The IPWSO COVID survey, which is still being conducted, indicates that the risks associated with developing COVID for people with PWS do not appear to be as bad as we had feared and now hopefully a vaccine will allow for life to return to what has been described as 'a new normal', whatever form that takes.

Over this last year, despite the pandemic, IPWSO has been very busy. After the great success of Cuba, Agnes took on her role as Communication and Membership Manager, later Marguerite became CEO and later still Nora joined as Project and Operations Manager. They are a most extraordinarily productive team. On behalf of all the Trustees I would like to thank them all for their enthusiasm, skill, and ingenuity. What has been achieved in 2020 would not have been possible without them.

Our core work remains providing advice and support to individual families, arranging genetic tests for those unable to get them, and ensuring information is available in a variety of languages. Central to much of what we do has been the work of the Website and Publications Committee, chaired by François Besnier. With Agnes's support they have overseen the launch of IPWSO's new website and logo. This is a great achievement.

James O'Brien, as Chair of the Project ECHO® committee, has seen the launch of our Leadership ECHO bringing together representatives from over 20 countries every two weeks. A Spanish speaking Latin American ECHO is starting in early 2021, this follows a huge amount of work conducted in 2020 by Amalia Balart to bring together the existing and emerging associations in the region to build capacity and reach more families. We will also be launching a Health ECHO and hopefully a Caregivers ECHO. The use of Zoom technology and the 'All teach all learn' philosophy of the ECHO Institute in the USA has transformed what IPWSO can do and how it does it.

Lynn Garrick and the Conference and Workshops Committee she chairs started the year with much planned, but face-to-face meetings have not been possible. The Committee has kept in contact with countries that had plans for 2020 and hopefully 2021 can be different.

Maria Libura chairs the Policy and International Liaison Committee that is working on policy development that has a global relevance for people with PWS.

President's report continued...

IPWSO has also engaged to a much greater extent at an international level particularly through Rare Diseases International and through taking part in initiatives to ensure that people with rare diseases have full universal health coverage worldwide.

Central to the work of IPWSO is the Fundraising and Finance Committee chaired by Marcello Schutzer. Their guidance and wisdom on all financial matters has been invaluable. Thank you to Marcello, Chair of the Committee, and to the committee members.

Our standing committees: 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 previously chaired by Amalia Balart and now by Verena Gutmann ensure that questions are answered, best practice developed and disseminated, and up-to-date information is provided. My thanks to the Chairs and to the standing committee members.

During the year we have received the most generous support from the Friends of IPWSO (USA) chaired by Joan Gardner, and also commitments for specific projects from Pfizer and Novo Nordisk. My thanks to them, their support has made much of what we have done possible. This year was also the first year we received a most generous donation from our Honorary President, Jean Phillips-Martinsson in memory of her son Anders and husband, Sven. Jean wishes to continue to support IPWSO in this way and we have established a fund named in her honour – Jean, thank you.

A big welcome to the Russian Federation and Hungary both of whom joined IPWSO this year. We look forward getting to know their membership and working with them.

My thanks to many others: the IPWSO advisers, particularly Colin Pearson and David Gordon have given us valuable legal advice; to volunteers, such as Jackie Gill who helped develop our mandatory charity policies and Tegan Elliott, who as an intern from the London School of Economics, prepared a report on international institutions.

A special thank you to the Board of Trustees who are inspirational.

Finally IPWSO is part of a larger family. I am grateful to our members for their support and for being part of IPWSO.

Chief Executive Officer's report

Marguerite Hughes



A commitment to unite the global PWS community has always been central to IPWSO's mission. As a result of the global pandemic, 2020 has indeed been a year when the world came together. With rapidly rising mortality rates, we were reminded how closely interlinked our communities are, how none of us are safe until we are all protected, and how international cooperation, human endeavour and a commitment to scientific discovery can offer hope of a better future.

In common with other organisations, some of IPWSO's activities were affected by COVID-19. We deferred our plans to support in person local conferences and workshops, and to host educational booths at medical conferences.

Nonetheless, 2020 was busy, productive and marked an expansion of IPWSO's activities. With great credit due to IPWSO's diagnostic testing partner, the Baschirotto Institute for Rare Diseases, our free diagnostic testing service remained available throughout the year. Our IPWSO ECHO® program began in April and as a result of a generous sponsorship commitment from Pfizer will grow and continue until at least early 2022.

During 2020, IPWSO expanded its role in international advocacy and IPWSO representatives participated in many online events aimed at improving the position of people with PWS and other rare disorders around the world.

IPWSO grew its research role with an ongoing study into how people with PWS have been affected by COVID, continuing work on choice and control for people with PWS, and a new research project focusing on residential care for people with PWS.

IPWSO's first full year as a registered charity in the UK required us to commit considerable time to aligning our governance systems to the requirements of the Charity Commission. 2020 also saw the creation of a new strategic plan that will guide IPWSO's work for the next three years and the development of our new website, which we hope will enable us to reach more people who need our help around the world.

IPWSO began 2020 with one part-time employee. It finishes the year with two part-time and one full-time employees. While the work carried out by IPWSO's employees has been instrumental to its achievements, as Figure 1 shows, IPWSO remains primarily reliant on the skills, commitment and energy of its volunteers. These include its Trustees, Advisors, Clinical and Scientific Advisory Board Members, Professional Providers and Caregivers Board Members, Famcare Board Members and many others who volunteer on its behalf. Without this tremendous voluntary effort, IPWSO simply could not survive.

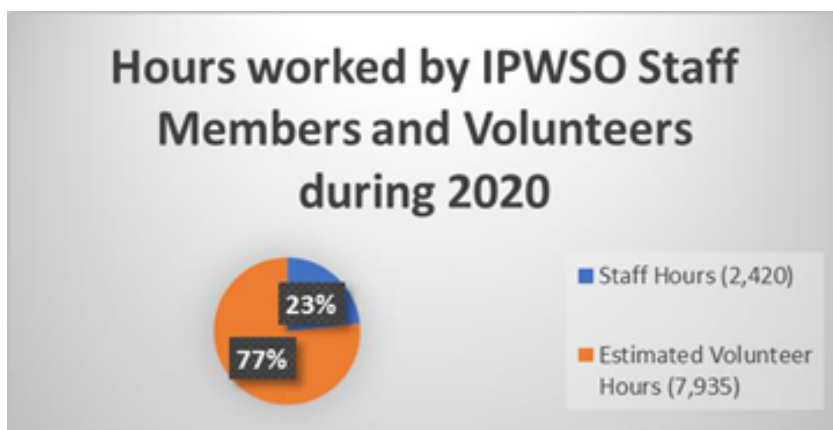
Chief Executive Officer's report continued...

IPWSO also could not survive without funding. Sincere thanks to all the PWS associations that paid membership subscriptions and gave donations, the many individuals who provided donations and organised fundraisers, Friends of IPWSO (USA), Interaction, and, in particular, Jean Phillips-Martinsson whose very generous donation enabled IPWSO to establish the Jean Phillips-Martinsson Fund in honour of Jean's late husband, Sven, and her late son, Anders.

In 2021 IPWSO will mark its 30th birthday. We will do so with pride at what has been achieved, yet conscious that people with PWS and their families continue to face serious challenges around the world.

There is much work still to be done.

Figure 1





FINANCIAL REPORTS



Treasurer's report

Marcello Schutzer, Financial Report for Year 2020

Despite all the challenges the world faced in Year 2020, IPWSO was able to maintain its commitment to the global PWS community. The organisation had to adapt its initiatives to a new world environment, and while we were not able to support conferences and workshops, we successfully launched our IPWSO ECHO program in April.

Since the beginning of 2020, we started managing our budget in two distinct groups: Restricted Budget, where the income generated by grants and donations is associated with specific projects and initiatives; and Unrestricted Budget, where the income is allocated according to the priorities defined by our Board of Trustees.

Below there is a summary of our 2020 financial results, divided by these two groups. The grants from Friends of IPWSO are listed in USD according to their original grant values. All other amounts are in USD equivalent, converted whenever revenue/expenses were in GBP or Euros using the prevailing rate on 31 December 2020.

Restricted Budget

During 2020, IPWSO received the following grants for specific projects:

- Friends of IPWSO granted \$15,000 to support conferences and workshops; due to COVID, we were not able to support conferences and workshops in 2020, so this amount will be added to the IPWSO meeting fund to be spent in 2021 or later.
- Friends of IPWSO granted \$30,000 which we spent on a revamp of our website.
- Interaction granted \$4,295 to cover costs of diagnostic testing; actual costs for diagnostic testing in 2020 amounted to \$2,910, and the balance of \$1,385 will be carried over to 2021.
- Finally, during 2020 IPWSO invested \$12,898 in Project ECHO, which will be funded by a grant to be provided by Pfizer in 2021.

Unrestricted Budget

During 2020, IPWSO received unrestricted sources of income in the amount of \$90,901, as detailed below:

- \$53,373 from the sale of 399.998 share units of Findlay Park Funds American Fund Unhedged (GBP), donated by Jean Phillips-Martinsson.
- \$28,682 donations from member associations and individuals.
- \$8,846 from membership fees.

Total expenses (from unrestricted sources of income) incurred during 2020 amounted to \$52,671, leaving a surplus of \$38,230. These expenses were incurred as follows:

Treasurer's report continued...

- \$37,704 in staff costs, which includes the CEO, 2 part-time employees and 1 full-time employee.
- \$8,045 to address financial reporting requirements of the Charity Commission and the virtual finance office.
- \$3,249 in office running costs.
- \$3,673 others (includes contribution to Clinical Trial Consortium, bank charges, insurance, associations memberships).

At the end of 2020, IPWSO maintained the following balances in our accounts:

- USD 59,550.39
- Euro 69,461.46
- GBP 53,029.43

In addition, at the end of 2020 IPWSO maintained 400 shares of the Compass Group plc, donated by Jean Phillips-Martinsson, valued at USD 18.73/share as of 31 December 2020.

Thank you to all of IPWSO's members who paid subscription fees during this difficult year, and thanks to those who also contributed with voluntary donations.

I also want to extend my sincere thank you to Friends of IPWSO (USA) and Interaction, for their support to key initiatives such as educational conferences, the IPWSO website and diagnostic testing.

Thanks to Jean Phillips-Martinsson, for her very generous donation that will enable IPWSO to keep serving the global PWS community and filling our families and members with hope and love.

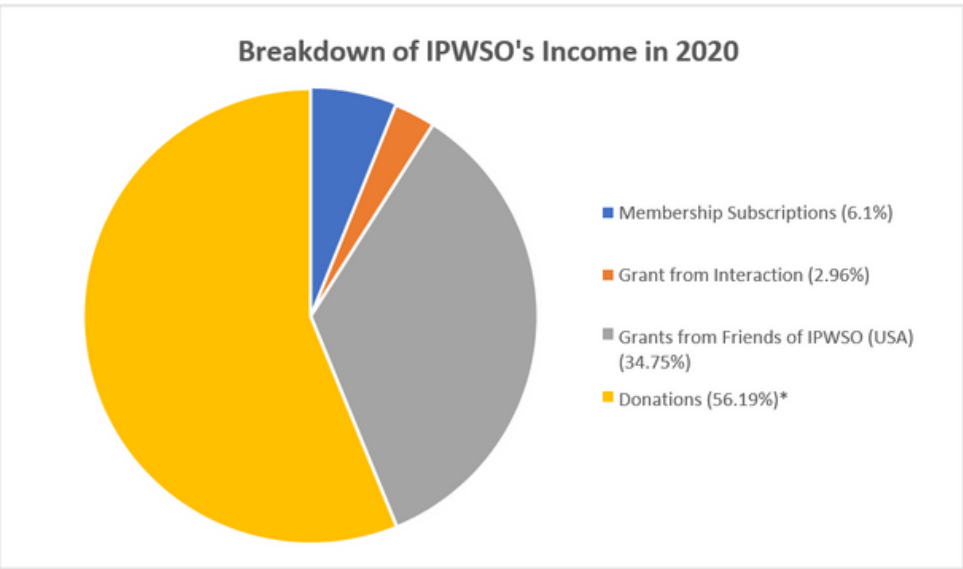
And a special thanks to Tony Holland and Marguerite Hughes, for their leadership and unwavering commitment to IPWSO.

2020 Funding Sources at a Glance

In 2020 IPWSO received funding from the following sources:

- 1. membership subscriptions from national PWS associations;
- 2. grants from Friends of IPWSO (USA);
- 3. grant from Interaction;
- 4. donations from individuals, organisations, and national PWS associations.*

No healthcare industry sources provided funding to IPWSO in 2020.



For more details on IPWSO’s 2020 accounts see its [2020 Audited Accounts](#).

*Note that the donations listed above include £39,062, which was received when IPWSO sold shares donated by Jean Phillips-Martinsson in 2020.

Receipts and Payments

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION Receipts and Payments Account for the year ended 31 December 2020

	2020 Restricted	2020 Unrestricted	2020 Total	2019 Restricted	2019 Unrestricted	2019 Total
	£	£	£	£	£	£
Receipts						
Donations - Corporate	3,143	-	3,143	-	2,389	2,389
Donations - Foundations	36,862	-	36,862	1,634	23,471	25,105
Donations - Members	-	12,564	12,564	-	-	-
Subscriptions	-	6,474	6,474	-	446	446
Other Fundraising and Donations	-	7,993	7,993	-	917	917
Funding donations	-	-	-	-	122,490	122,490
Proceeds from sale of investments	-	39,062	39,062	-	-	-
Total receipts for period	40,005	66,093	106,098	1,634	149,713	151,347
Payments						
10 th IPWSO conference costs	-	1,023	1,023	-	19,016	19,016
11 th IPWSO conference costs	-	-	-	-	40	40
Diagnostic testing services	2,130	-	2,130	-	-	-
Clinical trial consortium	-	815	815	-	-	-
Website, IT software & consumables	14,118	650	14,768	-	22	22
Project ECHO costs	-	806	806	-	-	-
Salaries	10,256	30,642	40,898	-	4,823	4,823
Pension costs	-	517	517	-	91	91
Travel scholarships	-	-	-	-	2,827	2,827
Bank charges	-	235	235	-	460	460
Accountancy fees	-	5,839	5,839	-	59	59
Foreign exchange	-	(235)	(235)	-	1,248	1,248
Insurance	-	619	619	-	188	188
Advertising and marketing	-	490	490	-	-	-
Office costs	-	1,223	1,223	-	220	220
Miscellaneous costs	-	704	704	-	-	-
Total payments for period	26,504	43,328	69,832	-	28,994	28,994
Net receipts being net movement in funds	13,501	22,765	36,266	1,634	120,719	122,353
Cash funds brought forward	1,634	120,719	122,353	-	-	-
Cash funds at the period end	15,135	143,484	158,619	1,634	120,719	122,353

Receipts and Payments

INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION Statement of Assets and Liabilities As at 31 December 2020

	2020		2019	
	Restricted £	Unrestricted £	Restricted £	Unrestricted £
Monetary Assets				
HSBC GBP	14,123	38,906	1,634	48,722
HSBC EUR	-	62,007	-	56,383
HSBC USD	1,012	42,571	-	15,614
Cash funds at end of the period: Total Monetary Assets	15,135	143,484	1,634	120,719
Liabilities				
Independent Examination & Accountancy fee for 2020	-	2,220	-	2,160
Bookkeeping fee	-	228	-	150
PAYE Payable	-	275	-	186
Pensions Payable	-	173	-	68
Total Liabilities	-	2,896	-	2,564
Non Monetary Assets				
Investment assets (note 6)	-	5,452	-	-
Total Non Monetary Assets	-	5,452	-	-

Approved by the Trustees and signed on their behalf by:

Marcello Schutzer
Marcello Giannubilo Schutzer
Trustee, Treasurer

Date: February 23rd, 2021



ADVISORY BOARDS



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](#).

Advice

The CSAB developed a standardized 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 various consensus documents which are available for our international audience.

Advocacy

The CSAB wrote a Letter to the Editor which has been accepted in the international journal Orphanet Journal of Rare Diseases advocating for the use of growth hormone therapy in adults with PWS.

IPWSO meeting in Ireland, July 2022

Planning has commenced for the International meeting in Ireland in 2022.

Monthly meetings

The members of the CSAB convene monthly by Zoom to discuss various pertinent topics.

Other matters

Numerous research clinical trials involving PWS are currently being conducted in different parts of the world. The CSAB is keeping abreast of these trials and will report on promising results as they become available.



Famcare Board

Verena Gutmann

As for all of us, due to the pandemic this year was a special challenge!

Our Board member Georgina Loughnan was quick enough to publish in a little while after the first lock down a Famcare article titled COVID-19 and PWS Guidance, to give some ideas about how to monitor the health of people with PWS and inform them about the impact of the virus on their lives. This year enriched our experiences about managing the lives of individuals with PWS during a challenging, global period. We learned about the benefits and the difficult consequences for families of people with PWS of being in “lockdown”. We had the chance to gather more “know how’s”.

In the summer I was asked to take over from Amalia Balart as the Famcare chair, and I agreed with the confirmation of the former committee to go on acting like a team.

One of the COVID-19 benefits is the increase of knowledge and experience with technical support like Zoom conferences, webinars, social media presence and of course the possibility of IPWSO’s new ECHO Project, to spread PWS knowledge around the world. This new challenge goes hand in hand with the duties of Famcare. We will try to work on this to help families in many corners of the world to have access to practical knowledge about PWS.

We will also continue to follow the well known path of making public articles which we consider reasonable and worthwhile. At the same time, we want to give energy to translating existing articles. All Famcare articles remain incredibly useful resources in managing PWS in daily life. We continue to look for new ways to present them again for example in social media.

If you know somebody who could help translate the Famcare articles into other languages, or to help with proofreading, please let us know!

In 2020 we held three online meetings, and we are proud to be working with, amongst others, María Elvira García, a very engaged mother from Colombia.

New articles are in the works and we hope that all our aims and visions can be achieved!

Professional Providers and Caregivers Board

Norbert Hödebeck-Stuntebeck



The routine three-year cycle of the PPCB meant a focus on planning for 2020, with no major events or conferences. And that's what we focused on initially with planning for the next three-day Caregivers Conference in Berlin, Germany 2021 with lectures and workshops.

But, towards the end of the year it became increasingly clear that due to the ongoing COVID pandemic, implementation of the Caregivers Conference as an event in person was no longer justifiable and the cancellation of the Caregivers Conference 2021 was the unfortunately necessary consequence. This makes us sad, because since the IPWSO conference in Romania in 2007 there have been events specially tailored to caregivers at regular intervals. In addition to the professional input, it was above all the personal exchange that pioneered the further development of ideas and approaches in this field.

However, as it is well known, in every crisis (or rejection) there is also an opportunity. And so the year 2020 ends as it began, with planning. The question arises: How can we, specifically geared to the focus of the caregivers, shape the expansion of knowledge, the development of new ideas and approaches in the care of people with the PWS under the globally changed framework conditions in the future? Here we are now working on ideas that keep old, tried and tested paths (if they are possible) and enable new constructive thoughts and approaches (online).

The aim always remains to provide the people who are in direct support of people with the PWS with the most qualified tools possible and to offer them for use across national borders and to improve implementation through training courses. In addition to these activities, another focus of the work of the PPCB was the regular online meetings in 2020 and spreading knowledge into the countries our members are based in and beyond.

It was also an intense concern to take into account the special perspectives, visions and needs of the group of caregivers in the entire "PWS family" during the IPWSO board meetings, in a very dynamic year for the organisation.

Finally, let me say a few words on my own behalf, as I will hand over the role of Chairman of the PPCB to my successor in the middle of next year (at what would have been the "Berlin Conference") and go on as a regular member of PPCB. During the entire time since the PPCB was founded (in 2010 in Taipei, Taiwan), it has been a special honour for me to be able to work with so many committed and competent PPCB board members, IPWSO board members and presidents. Over this period we as PPCB have succeeded in giving the caregivers a visible and permanent place in the "PWS family" in addition to people with the PWS, parents and scientists and clinicians in IPWSO.

Professional Providers and Caregivers Board continued...

Thank you very much for so many positive experiences and the many great people I was able to get to come into contact with during this entire time.

My special thanks go to the current PPCB board members: Mary K. Ziccardi (Co-Chair), Hubert Soyer, Larry Genstil, Jackie Mallow, Damien Jones, Neil Gumley, Laura Keane, and Patrice Carroll.



PROJECTS

Conferences and workshops

Lynn Garrick



The Conferences and Workshops Committee has not been as busy as it would have liked to be this year due to the limitations of COVID. We did receive a total of nine applications for assistance to host workshops. The committee remains in contact with the applicants and is hopeful that virtual conferences or small workshops will be possible in some cases. The committee is developing a virtual library where countries wishing to host a conference or workshop can access different presentations on various PWS topics that can be used for virtual conferences so applicants can tailor the workshops to their specific interests. The committee remains committed to assisting with in-person meetings when travel is allowed and safe and will happily announce when this is possible.

The Asociación Colombiana Síndrome de Prader-Willi organized an impressive series of online seminars during 2020. Norbert Hödebeck-Stuntebeck and other members of the Professional Providers and Caregivers Board were delighted to be involved. They spoke on a range of subjects, including preventing crises and managing social and emotional difficulties.

In November, Prader-Willi Syndrome Malaysia hosted a conference bringing together 200 participants, including parents, people with PWS, allied health professionals, and students, who were all able to interact with a panel of local and international IPWSO speakers, including our Vice President James O'Brien. Participants attended from Malaysia, with overseas delegates joining remotely from Japan, Vietnam, Australia, New Zealand, Hong Kong, Bangladesh, Thailand, India, US, Peru, Russia, and Lebanon. It took eight months of hard planning for the association during a challenging and uncertain year, and we were delighted to see the event be such a success.

In December Tünde Liplin and the Hungarian PWS association hosted an online conference, inviting Susanne Blichfeldt to present on behalf of IPWSO. The event was attended by 40 participants, including members of 24 families and 2 endocrinologists. The conference covered a wide range of topics about PWS and Susanne responded to many questions including concerning genetic subtypes, symptoms and treatments.

**The 11th International Prader-Willi Syndrome
Organisation Conference, University of Limerick campus,
Ireland, 6 – 10 July 2022
Nora McNairney**



In partnership with PWSAI, IPWSO is delighted to host the 11th International Prader-Willi Syndrome Conference in Limerick, Ireland from 6 to 10 July 2022.

The Planning Committee, spearheaded by representatives from the following programmes met on five occasions throughout the year and undertook a site visit in early Spring:

- Clinical and Scientific Programme;
- Professional Providers and Caregivers Programme;
- Parents' Programme;
- Interdisciplinary Programme;
- Adults with PWS Programme, and
- the Programme for Children with PWS.

Despite the uncertainty with COVID-19, the Committee has focused on tentative arrangements for an in-person conference, whilst also exploring what a virtual conference experience might deliver.

Committee Members from each of the programmes have also been meeting to consider the format, content, and to identify speakers.

Giving recognition to the fact that PWS is a complex, genetically determined, multi-disciplinary disorder that requires different skills and perspectives, and ideally a multi-disciplinary approach, we have introduced an additional programme for 2022. This one-day inter-disciplinary programme is aimed at both health and allied professionals, including but not limited to teachers, physiotherapists, speech therapists, psychologists and social workers, and offers these professionals the opportunity to understand the need for a holistic approach to the health and social care requirements of people living with PWS.

Planning is underway for an event "stepping up for PWS" that will occur over Saturday and Sunday of the conference. This event will be for people with PWS aged 18 and older. There will be classes on various topics during the morning and activities at the university's activity centre in the afternoon. This programme will be a first of its kind to be offered at an IPWSO international conference. We are very excited to offer this and look forward to sharing more information as the planning advances.

The 11th International Prader-Willi Syndrome Organisation Conference continued...

An exciting programme of social activities is planned too, and we will host a Members' event to provide an opportunity for newer groups to meet with more established associations.

A huge thank you to the Committee Members for all their work; our International Conference takes a great deal of volunteer time, commitment and energy and is made more difficult in these uncertain and frustrating times, but is so rewarding when we witness how it reinvigorates practice, provides opportunities for new friendships and supports, and disseminates learning and new ways of working.

Whatever the format, we encourage you to Save the Date and visit our website to keep apprised of developments. And, we do hope to see you in person, in Limerick, in 2022!



Project ECHO® James O'Brien

In 2019 we reported on our plans to develop an online PWS telementoring community, designed specifically for people who wish to grow and develop PWS associations and build knowledge and understanding of the syndrome in their countries. In April 2020 we launched the first pilot session, the IPWSO Leadership ECHO®. Over the course of nine sessions, we brought together subject experts, PWS associations, parents, health and allied professionals and professional caregivers from across the world to discuss and debate a wide range of subjects which impact on the lives of people living with PWS and their families. We discussed the syndrome, best practice, service developments, social care and employment issues as well as how, we as leaders, or potential leaders, can foster links and create networks to assist us to make positive changes in our countries.

We received news in the Autumn of 2020 that our application to Pfizer Inc., for a Medical Educational Grant to help drive this initiative forward, was successful, enabling us to expand and develop our ECHO programme. We launched a new round of the Leadership ECHO in December, a Health ECHO is planned for February 2021 and an ECHO specifically for Latin America and Spanish speaking countries will start in March.

The Leadership ECHO programme has attracted PWS associations from across 25 countries and on average 22 participants attended each Session. The feedback illustrates the benefits to be derived from coming together to build networks and share experiences:

"Learning about good practice in other countries gives me great hope."

"I loved this presentation and I will share it with my daughter's teachers and with other parents."

"Today's topic and its discussion on the transition from school to adult life is so relevant to children with PWS. The odds seem insurmountable at first, but when we hear them presented in the IPWSO Leadership ECHO®, it shows that every country faces the same predicament. Some have started the race, and some are still preparing to do so."

"Every session was a big help for me! Thank you all!"

However, there is still much to do to cover all the topics that participants have requested and to expand our reach across the continents.

Project ECHO® continued...

We are grateful to all those subject experts who gave presentations over the course of the year. They generously shared their knowledge and understanding and, by permitting us to capture their presentations into short films, amplify our capacity to deliver best-in-practice care, current and knowledgeable information on PWS.

Very many thanks to Tony Holland, Georgina Loughnan and Amalia Balart who are core to the success of the ECHO project and volunteer a great number of hours; their tasks are many and varied - planning, facilitating, leading and chairing. Their expertise and knowledge keep us on track and challenge us to think about how we can best utilise our resources to build capacity and better serve people with PWS in our countries.

Thanks also to David Gordon and Colin Pearson who provided essential legal advice and to Janelle McIntosh, PWS Australia, who assisted in the early stages of development.

We are indebted to Pfizer Inc. for their financial support. Marguerite Hughes worked very hard to secure the funding, without which we would not have been able to employ our two Project Managers, Nora McNairney and Shelly Cordner (starting in 2021) - Nora and Shelly will provide the equivalent hours for one full time member of staff.

We also extend our thanks to the University of New Mexico and the ECHO® Project for providing us with the framework and Zoom technology that makes this initiative possible. Ellie Cordova, as our Account Representative at ECHO, has been a great resource providing guidance and ensuring we remain faithful to the ECHO model.

Finally, very many thanks to our participants whose contributions - insights and enthusiasm - encourage and sustain what is genuinely becoming a global PWS ECHO community, of which IPWSO can be deservedly proud.



Policy and research

Maria Libura

COVID-19 study

Early on in the COVID-19 crisis Professor Tony Holland and the Clinical and Scientific Advisory Board set up a study into the effects of the COVID-19 infection on people with PWS. The results of the survey are still coming in and are being analysed by Dr Joyce Whittington at the University of Cambridge. The extent to which COVID-19 is affecting us varies from country to country, we have seen over 40 responses so far and generally the effect of COVID-19 on people with PWS has been mild, which is very positive news, but surveys are still coming in and the more answers we have across as many countries as possible the more we will learn. The survey was published in English, French, German and Spanish and is to be completed by a parent or carer. We hope that the results will help us understand more about how COVID-19 affects people with PWS so we can be well prepared both now and in the future.

Research on specialist services for people with PWS

There is significant anecdotal evidence that PWS-specific residential services bring benefit and are necessary for many people with PWS if they are to have satisfied, socially integrated and healthy lives. However, there are very few peer-reviewed evaluations of these services. Without formal empirical evidence of efficacy, it has proved difficult for countries who lack such services to argue that they are necessary, and even in many countries where such services exist it has proved difficult to develop additional services. By working with care providers from around the world, IPWSO aims to evaluate PWS residential services.

Choice and control: the use of restrictive practices in the care of people with Prader-Willi syndrome

IPWSO and Elizabeth Fistein of the University of Cambridge are conducting research to find out more about people's views on the best way to support healthy lifestyles for people with Prader-Willi syndrome, whilst ensuring their rights are respected. A huge thank you to everyone who has participated in the survey on supporting people with PWS to manage hyperphagia. We have had responses from people from all around the world and it has been wonderful, and extremely informative, to hear from you all. The research team is now in the process of analysing all of the responses, in order to produce a report that will feed into new draft guidelines. We plan to circulate the first draft of the guidelines in the early part of 2021 and look forward to hearing your views and incorporating your perspectives. We plan to use the results of this research to help us to develop guidelines on how to support healthy lifestyles for people with Prader-Willi syndrome, whilst ensuring their rights are respected.

International Advocacy

Marguerite Hughes



International advocacy on behalf of people with PWS and their families is a role that IPWSO is uniquely placed to fulfil. While advocacy and engagement with international bodies have always formed part of IPWSO's work, during 2020 the IPWSO Trustees decided to intensify its efforts in this area.

This work was given impetus by Tegan Elliott, an IPWSO intern who produced a report on how IPWSO could maximise its impact at a global level. This included consideration of organisations that IPWSO could collaborate with and identities that may be relevant to people with PWS: people with a rare disorder; people with a genetic cause of obesity; people with a syndrome associated with endocrine abnormalities; and people with developmental disabilities.

By the end of 2020 IPWSO had established formal links with EURORDIS, Global Genes, Healthcare Information for all (HIFA), the International Alliance of Patients' Organizations (IAPO), the International Conference of Rare Diseases and Orphan Drugs (ICORD) and Rare Diseases International (RDI).

As part of this work IPWSO was delighted to support Universal Health Coverage day in December and to participate in RDI's consultation process on the proposed WHO Collaborative Global Network for Rare Disease Centres of Excellence. Through our representation on the Global Genes RARE Global Advocacy Leadership Council, IPWSO expanded its influence into other rare disease communities, sharing our knowledge and awareness and learning new organisational skills and advocacy practices.

IPWSO also continued its collaborations with the Prader-Willi Syndrome Clinical Trial Consortium (PWS-CTC), and a range of scientific societies, including the European Society of Endocrinology (ESE), at whose September conference IPWSO held its first ever virtual awareness booth.

While looking forward to continued engagement and collaboration with international partners during 2021, we remain constantly aware that it is only through our close connections with our members and contacts that IPWSO is able to represent the needs of our community and explain the challenges facing people with rare disorders in general. For that reason, our heightened focus on international advocacy is matched by our commitment to fully understand the realities facing our members and contacts, whatever their experiences and wherever they live.

Diagnostic testing at the Baschirotto Institute for Rare Diseases (BIRD)

Marguerite Hughes



For the 18th 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.

Despite COVID and the challenges it brought, the Baschirotto Institute remained fully operational throughout 2020, for which we are very grateful.

All 20 diagnostic tests conducted on behalf of IPWSO in 2020 were paid for through a generous grant from Interaction.

Since the inception of its free diagnostic testing service, IPWSO has funded testing for over 500 families around the world. As far as we are aware, IPWSO is the only organisation that provides this service for PWS or any other rare disease.



Website and publications

François Besnier

The Website and Publications Committee has been working mainly on two topics over the past year. The first one was redeveloping a new website and repositioning and updating the IPWSO brand. The second one was reflection and strategy about publications and plans for the future.

Website and brand

In addressing our website we wanted to better reflect our big ambitions to provide high quality information and support to families, associations and professionals around the world. Our website is a key tool for doing this and thanks to funding from Friends of IPWSO (USA) we have successfully redeveloped our site to make it much easier for visitors to find and use our resources.

Knowing the importance of social media and that many people access information on their phones we knew that we also had to improve how we presented our information. At the same time as redeveloping our website we have also created a new logo and IPWSO colours to highlight our role as an international organisation and give a fresh, modern and appealing look to our materials.

Our new logo symbol is formed of six shapes representing the continents we work with across the world and the global reach of IPWSO. They are linked to communicate our aims, goals and achievements in bringing PWS communities together. There are six distinct colours to show that Prader-Willi syndrome is not a selective condition – it affects all cultures, ethnic groups and genders equally.

The new website was launched at the end of November and our new image is also reflected across our social media profiles.

Publications and plans for the future

IPWSO has gathered since its creation a set of rich materials, produced by our experts and advisers. The committee has started to audit these existing materials in order to identify the possible gaps, duplication and papers which are now redundant.

The committee has worked with the Communication and Membership Manager to oversee the development and implementation of a coherent design for all publications in order to make our information easier and more attractive to access and read. The language and translation issues question has been addressed for a better coverage of the countries' needs. The committee has set up guidelines for the development of a coherent communication and publication strategy using various media going forward including the website, emails, newsletters and social media.

Advice service

Agnes Hctor



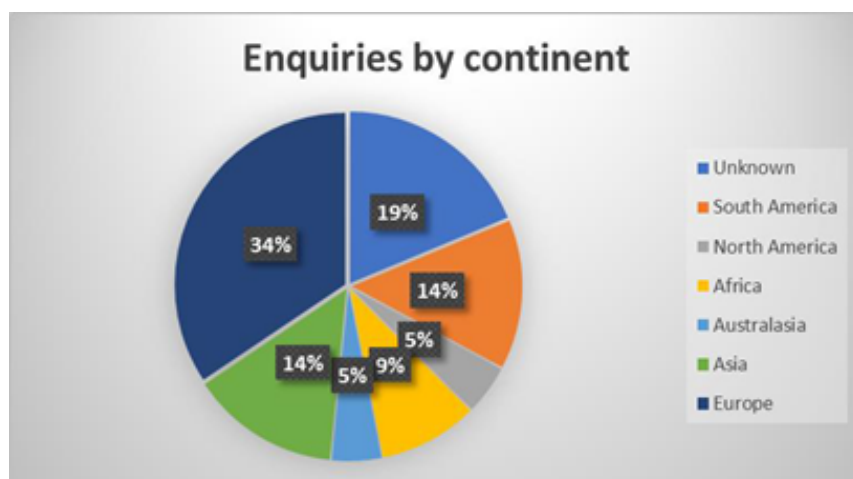
In 2020 our advice service responded to 70 enquiries from people around the world covering a wide range of different issues. We heard from parents and siblings, desperate for information and support, people with PWS with questions about their own lives, medical professionals and caregivers looking for expert knowledge to support their patients and clients.

Enquiries came from 35 different countries including many from Eastern Europe and South America. Some came from countries which have IPWSO member associations and we were happily able to pass the correspondent over to their national experts, but the majority came from countries with no central PWS association and little expert knowledge. With IPWSO contacts in over 100 countries worldwide we were able to use our network to link people up and direct them to useful information and resources.

The main theme of the enquiries was of families wanting support, to be linked up with other parents or professionals in their country.

Responding to enquiries is a team effort and we must give many thanks to the IPWSO Boards and Advisors for all their valuable input in drafting these responses.

The advice service continues to be an important part of our work and feeds into other areas such as the importance of developing our Project ECHO® support, translated guides and workshops in diverse parts of the world.





ABOUT US

About Us

We are an international, parent-led, non-profit membership organisation supporting national Prader-Willi syndrome associations, as well as people with PWS, their families and the professionals who work with them.

As an international umbrella organisation we bring together the national Prader-Willi associations, and for countries where there are no formal associations, we support medical and parent delegates as part of our global community.

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What is Prader-Willi syndrome?

Prader-Willi syndrome (PWS) is a complex genetic disorder characterised by low muscle tone and failure to thrive at birth, and later evidence of short stature, intellectual disabilities, behavioural and psychiatric challenges, and the development of a chronic feeling of hunger that results in over-eating and in severe obesity and associated health problems.

Multiple studies have shown that between 1 in 15,000 to 30,000 people in the populations studied have PWS, which occurs equally across all races and both sexes, although life-expectancy and population prevalence globally may differ depending on the availability of an early diagnosis and of information, treatments, services and supports.

IPWSO is committed to supporting all people with PWS and their families, whatever their needs, and wherever they live.

Support IPWSO

We can only carry on our work thanks to the support of our members, volunteers, donors and supporters. Please consider supporting us this year, thank you.

- To donate please visit us at 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.