

The International Prader-Willi Syndrome Organisation (IPWSO)

From The Beginning...

**by Jean Phillips-Martinsson, Honorary President
Founder of IPWSO,
President 1991-1998**

These are the highlights of my 15 years' involvement with the creation of IPWSO and its administration. It is a record taken from my files and a token to all those parents and professionals who supported and worked alongside me. This is no attempt to cover the history of Prader-Willi Syndrome and the remarkable scientific advances made into the research and management of the Syndrome during that period. It would be impossible for me, a layman, to select the most important ones, which is why no credits are given. Suffice to say, we're so lucky to have such an engaged, competent team of scientists and professionals who share our goals to improve the quality of life for all people with PWS and their families.



My goal was to develop an international umbrella organisation which would stimulate collaborative research and reach out to all corners of the globe to identify and bring together our sparse PWS population. We are well on the way, but much still needs to be done. The development of Internet has helped this cause enormously. It is my hope that those who continue with the task may find some tips of what to do, and what not to do, in this short history!

Bon voyage IPWSO and all who sail with her!

Introduction

Jean and I first met at a PWSA (UK) conference in the late 1980s. She was the one standing up in the audience and asking the questions the doctors could not answer. Even then, her determination to get at the real answers to PWS marked her out as a force to be reckoned with. Her energy and tenacity have well-served everyone in the PWS world ever since.

It was Jean who conceived the idea of an international PWS organisation, and Jean who persuaded a few countries to get together to organise a conference to bring together all the experts in the world in order to pool their knowledge and expedite research into PWS. As first President of the fledgling IPWSO, she was able to use her background in international cultural affairs to forge links between individuals and countries, which has formed the basis of many ongoing friendships and sharing of vital information.

I had the privilege of working with Jean during her second term of Presidency, when I was Hon. Secretary of IPWSO. She always impressed me with her breadth of vision, but also the attention to detail she gave to her work. Without these two qualities driving it forward, IPWSO would not be the strong organisation it is today.

Jean is not “just a parent”. She has been one of the prime movers in the PWS world and her selfless commitment to help parents and people with PWS over the years is an example to us all that visions can become reality.

Jackie Waters
PWSA UK

From the beginning....

1984

Anders (14 yrs), our son, is diagnosed in Sweden with PWS. We're told it's very rare, that little is known about it and that no other cases are diagnosed in Sweden.

1985

The hospital finds an article on PWS written by Dr. Laurence (UK) which mentions **that a parent organisation (PWSA-UK) was formed in 1981.**

As Anders is then at school in the UK, I pay a visit to Dr. Laurence. He confirms Anders' diagnosis and tells me to get in touch with his Swedish colleague, Prof. Martin Ritzén who is Head of Pediatric Endocrinology at the Karolinska Hospital, on my return to Stockholm.

1986

It turns out that Martin Ritzén has diagnosed 4 families with PWS and is much more optimistic about their future, provided an early diagnosis can be made. He cannot divulge their names for ethical reasons. He agrees to forward my letter to the families inviting them to coffee on 19th April and launching the idea of forming a Swedish PWS Association.

The waiting is intolerable - what will they be like? Do we really want to know what the future holds after 14 years in limbo? They all turn up aged 15-26 and meet others with PWS for the first time. It is an extremely emotional situation for us all. The 26 yrs-old is so large, she can't sit down properly. She was only diagnosed at 22 years. The family describe the hell they've been through. We all decide that we'll never let our offspring get to that size. But will we be able to prevent it? So little is known about PWS at present and so little help is available .

On **8th June, 1986, the PWSA-Sweden is formed**. 7 families participate. Martin Ritzén becomes our Scientific Advisor and I am elected Chairperson. Some families tell about their contacts with the **PWSA-USA, formed in 1975**. Researchers there are increasingly studying the causes and effects of PWS. In November, we participate in the PWSA-UK annual conference in Bristol. By the end of the year we have some 20 families all desperate to know more about PWS.

And so the urgency to "go international", to share research and experiences and to strive for an early diagnosis begins to emerge and the seeds are sewn to create some form of international PWS collaboration. But Sweden, on the tip of the Northern hemisphere, with a language only spoken by its 8 million inhabitants and a handful of Finns, was hardly the ideal country from which to "go international"!

Finding the right contacts overseas and communicating with them by post would take forever. (Faxes were few and far between and computers non-existent in those days).

The Danish and Norwegian PWSAs are also formed during the year.

1987

On a business trip to the Netherlands, I discover that they too formed a **PWSA Netherlands in 1985** and contact their Chairman, Henk Moezelaar. Henk and I begin to share the dream - two small countries with small languages and minute PWS populations need to collaborate with other countries if our voices are to be heard. We begin to discuss the idea of organising an International PWS Conference in Holland to assemble the few experts on PWS worldwide and their

patients, to share information and encourage collaborative research. We agree that to do this we must involve the PWSA-USA who are way ahead in their research.

We write to Marge Wett, Executive Director PWSA-USA, launching the idea.

The only PWS-Associations in existence at this time are **USA (1975), Canada (1978), Australia (1979), UK (1981), The Netherlands (1985), Denmark, Norway, Sweden (1986) and Belgium (1987).**

1988

We receive a letter from Dr. Suzanne Cassidy (USA), Associate Professor of Pediatrics, University of Arizona College of Medicine, telling us that she would be interested in organising such an international conference and in chairing the Scientific days. It is agreed to hold the conference in 1990 in Holland. She will apply for North Atlantic Treaty Organisation (NATO) funding to cover scientists' expenses. The Dutch will apply for European Union (EU) funding for parents and professionals. We also take up contacts with The World Health Organisation (WHO) who, although unable to provide funding, send us a telegram wishing us luck and giving us their official approval to use their name on our invitations and programme. So, although PWS is still not registered as a handicap in many countries, these World Organisations have us on their books which should make it easier for delegates to apply for funding!

The first Nordic PWS Experts' Meeting is held 11-12 April at the Frambu Centre, Oslo - a Centre where Norwegian families with Rare Disorders are invited to spend two weeks together and meet with doctors, physiotherapists, psychologists, dietitians etc., while their children attend school lessons or kindergarten. Medical experts, and a handful of parents, come from Denmark, Finland, Iceland, Norway and Sweden. **PWSA-Sweden become members of the RBU** (The Swedish Association for Physically Handicapped Persons) who, in 1992, are to sponsor the foundation of our International organisation.



1st Nordic PWS Experts' Meeting 11-12 April 1988 at Frambu Center, Oslo. Dr Stefan Hreidarsson (Ice), Socialworker aija-Liisa Hokkanen (Fin), Prof. Martin Ritzén (Swe), Jean Phillips-Martinsson, Chair PWSA (Swe), Psyk. Birgitta Böhm (Swe), Dr Susanne Blichfeldt Chair PWSA (Den), Neurolog Hilka Schugk (Fin), Anne Lise Haanes, Chair PWSA (Nor), Dr Jona Haldersson (Ice), Dr Arvid Heiberg, Frambu (Nor)

1989

Intensive correspondence follows throughout the year. Susie Cassidy and Martin Ritzén contact their professional colleagues to initiate their collaboration and inform them about the conference. Martin asks them to provide me with a parent contact from their countries. Marge Wett too contacts all the overseas members of the PWSA- USA.

The Dutch are beginning to query if there really is enough knowledge and interest in PWS in Europe to organise an international conference on it. We test the case in Sweden and organise a seminar on PWS which is held at Karolinska Hospital in Stockholm on 13th April. We anticipate a participation of some 20 doctors but are encouraged and delighted when 190 turn up from all over the country! Our guest speaker is **Dr. Vanja Holm** from the Child Development and Mental Retardation Center (CDMRC) University of Washington, USA - the first clinic to use an interdisciplinary team approach to assess children with PWS. Vanja, who is born in Sweden, presents an overview of PWS and informs about her clinics where PWS families have access to pediatricians, nutritionists and behavioural-psychologists.

Susie Cassidy, Henk Moezelaar and I meet at last at the 11th Annual Conference of the PWSA-USA in Calgary, Canada, July 19-22 and decide to postpone the international conference until 1991. This will give us more time to plan and organise funding. **We form the Organising Committee.** The first planning meeting for the International Conference is held.



I'm taller than you! Vanja Holm (USA) and JPM (SWE) in Stockholm



*PWS Conference Calgary, Canada, 19-22 July, 1989
Susanne Cassidy (USA), Henk Moezelaar (NL) and Jean
Phillips-Martinsson (SWE) form the Organisation
Committee and meet in Calgary to plan the 1st International
PWS Conference to be held in the Netherlands.*

Association du Syndrome de Willi Prader (ASWP) is formed in France. **PWSA-New Zealand is formed.**

1990

In January, Susie Cassidy, Louise Greenswag, Susanne Blichfeldt, Henk Moezelaar and I meet at the Congress Centre in the Netherlands.

Louise Greenswag (USA), together with Dr. Susanne Blichfeldt from Denmark, will organise the educational part of the programme for parents and professionals.

In October Henk Moezelaar and I visit the Leeuwenhorst Congress Centrum in Noordwijkerhout and book the conference. Numerous meetings with Henk in Holland and Susanne Blichfeldt in Denmark are held.

After 3 days of searching, Le Centre de Recherche Medicale in Paris inform me that PWS is known in France as Willi Prader. That explains why my enquiries have drawn a blank during the past 6 years!

PWSA-South Africa is formed.

Kabi-Pharmacia agrees to sponsor our conference by promoting it at all their own international gatherings and at those in which they participate. They will also fund a Swedish medical journalist to cover the proceedings and place his articles in the Swedish medical, psychological and dietary journals. Member countries are encouraged to do likewise and so spread information about PWS. Professor Andrea Prader is contacted and asked to give an opening talk.



A meeting of the minds in Calgary! Terry James (CAN) and Sven Martinsson (SWE) discuss Terry's Canadian studies of PWS which were published in 1992 in a book entitled "Home, School and Community".

The first announcement goes out in May. We are now drowned in correspondence from all over the world mainly asking about funding! Many "official" letters of support for sponsorship are written for them to pass onto their local governments, authorities etc. We now have contacts with many new countries including **Japan, South Africa, New Zealand, Namibia, Belgium, DDR, Germany, Greece, France, Italy and Poland.**

A meeting is held in Holland to discover the interest in forming an **European PWS Association**. This meeting, initiated and **hosted by Henk Moezelaar**, was attended by **Belgium, Denmark, The Netherlands, Norway, Sweden, Switzerland and the UK**. It was thought, amongst other things, that an European body would find it easier to attract funding from such organisations as EU. It was finally decided to shelve this project when this theory proved to be invalid. The EU, for example, will consider backing projects so long as at least 3 European member countries participate, whether or not they belong to an European Association. It was also felt, especially by the non-European PWS Associations, that the small PWS population should stick together and concentrate on forming a strong worldwide International Organisation. In the future as we grow, it may well be a good idea for continents, or regions, to build their own organisations, but preferably under the umbrella of an International Organisation.

1991

All International Handicap Associations are sent a press release for their journals, as are the most important scientific journals.



Dr Prader was invited to the 1st International conference

The 1st International PWS Conference is held 2-5 May at Leeuwenhorst Congress Centrum in Noordwijkerhout, in The Netherlands. The decision is taken to entitle this conference PraderWilli Syndrome and other Chromosome 15q Deletion Disorders in order to attract a wider audience than those few who are familiar with PWS. Some 200 delegates attend from 22 countries. Commenting on this in his opening talk, **Prof. Prader** says: "As one of the authors who first described this syndrome in 9 patients aged 5 to 23 years in 1956, I am happy to be alive to witness the increasing interest among pediatricians and geneticists for this syndrome "Concerning management, we have learned from the parents more than they from us...."

At the meeting, the identification of a marker for the chromosomal region 15q11-13 which could be used for direct molecular genetic diagnosis of PWS was presented. Scientists could then work together to formulate the clinical criteria for diagnosing PWS. (This was finally published in 1993.) A report on the effects of GH treatment on 10 PWS children with PWS was given. Most of them responded well and it was suggested that "patients with PWS were potential candidates for GH therapy", supporting a previous case study in 1987.

It is announced at the meeting that the first **European group-home**, designed specifically for 5 PWS adults, is **to open in Stockholm, Sweden in 1992**. Each of the 5 residents will have their own 50 sq.m. apartments but share a common area with the staff where all meals will be taken. One of the highlights of the social programme is a spontaneous performance during the evening by Percy Samson, a carer from Sweden, and Dr. David Graham (NZ) who share a guitar and sing for and with us.



Keukenhof Tulip Park - Holland. Serina and Esther K n z (CH) with JPM

As parents, these 4 days are emotionally draining - so many new medical terms and exciting research projects to understand! But how long will we have to wait before our children can have any benefit from them? On the other hand, to hear all these international experts so engaged in PWS is most encouraging. Maybe the greatest thrill, however, is to meet so many wonderful families from totally different cultures and backgrounds, yet who share the same PWS life-style. In fact, for once nobody asks us that eternal question "PWS what's that?"



*Founding of IPWSO at 1st International PWS Conference in Holland 2-5 May, 1991. Jean Phillips-Martinsson (Swe) is elected President
Sven Martinsson (Swe), Alicja Borek (Pol), Ross Parker (Can), Anders Martinsson (Swe), JPM, Vanja Parker (Can), Elzbieta Drozdowska (Pol)*

THE INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION (IPWSO) is formed on 4th May.

One parent delegate from each country attends the foundation meeting. The name and its objectives are unanimously approved and I am elected President. It is agreed that each country which has formed their own national PWS Association may become members of IPWSO. They should appoint one professional and one parent delegate to represent them at IPWSO.

On returning to their countries, members receive a protocol of the Foundation Meeting, written by Julien Courtauld, Chairman of PWSA-UK. A form is attached, asking them (a) to confirm their Association's approval to appoint me as President, or nominate another candidate from their own country, (b) to nominate their own candidates to sit on the Board and (c) to provide the names of their country's Professional and Parent Delegates. The first Board is constituted as follows:

Jean Phillips-Martinsson (SWE) President
Julien Courtauld (UK) Vice-President
Piet van Oosten (NL) Treasurer

Marge Wett (USA),
Linda Thornton (NZ)
Birgit Schroeder (SA)

The Board gets to work. Lengthy discussions on ways to fund IPWSO continue into 1993 when it is agreed that subscriptions should be pro rata the number of members:

1-49 members	\$ 50	50 - 99 members	\$100
100-299	\$200	300-500	\$500
over 500	\$1.000		

During these first two years, Board members have to cover their own administrative costs. The first proposal is for \$2 per member but this is turned down flatly by USA, amongst others, who point out that they would be funding 72% of IPWSO's administrative budget.

Statutes are drawn up, with the help of PWSA-UK and 3 other International Handicap organisations' Statutes, and sent to the Board for approval. The idea of an **IPWSO Newsletter** for parents is launched and approved, as is the idea of having an **IPWSO brochure and logo**.

PWSA-Germany is formed.

Both **UK** and **Norway** offer to host the next International Conference. The need for holding these conferences every 3 years is recognised, due to the acceleration of PWS research projects taking place. The UK is elected to hold the next one in 1994.

1992

PWSA (Italy) is formed. Enquiries are received from **Austria, Finland, Japan, Poland and Spain**.

The Swedish Association for Physically Handicapped (RBU)- now the umbrella organisation of PWSA-Sweden, **offers to take over IPWSO's Secretariat**. To cover these costs, and some of my administrative and travel costs, they agree to make available a maximum sum of **\$5,000 per annum** during my Presidency, and/or until such time IPWSO can stand on its own two feet.

Linda Thornton (NZ) offers to become **editor of IPWSO's newsletter for parents** and suggests the name "Wavelength". Under her editorship, it will soon become the mouthpiece for everyone involved in the management of PWS. The first edition is published in December. It is a "getting to know you" one where each country describes its' Association and membership and what they try to achieve. A list of professional and parent delegates is also attached. Two editions per annum are planned. The need for a scientific version aimed at professionals is discussed, but is difficult to get off the ground as scientists are so busy.

The IPWSO brochure is drafted by Julien Courtauld (UK) and circulated to the Board for approval.

Piet van Oosten (NL) and I attend meetings in Brussels with the **EU's Handicap**

Committee and with the International League of Societies for Persons with Mental Handicap (ILSMH) to inform them about IPWSO and check on the possibility of funding. We also look into the idea of becoming Associate members of ILSMH. We decide to put this on hold until our Statutes are approved at the next General Assembly and IPWSO is registered as a Charity.

Statutes are finally approved by the Board. It has taken us over one year to collect all Board members' recommendations and pass them over to one another by snail mail and fax! There is much collaboration with PWSA-UK to organise the 2nd International PWS Conference to be held in Cambridge from 30th June-3rd July 1994. Many meetings are held with various international handicap organisations to study their ways of financing their operations. None have acquired funding for their administration. Such financing must be acquired nationally. As stated previously, funding from EU is available for research projects, international conferences etc. so long as at least 3 European member countries are involved, and the project is realised in one of them.

Marge Wett retires as Executive Director of PWSA (USA) and steps down from our Board, as does Piet who also retires. Julien Courtauld takes on the role of Treasurer.

1993

On 15th April IPWSO is at last registered in Stockholm as a Charity No. 8020171776. It has taken this long as we a) had to present the finalised version of our Statutes and b) the authorities wanted it translated into Swedish.

Janalee Heinemann (USA) joins our Board. **PWSA-Finland is formed.**

In June, a letter is received from the Chairman of the UK Conference Organising Committee cancelling the 2nd International Conference to be held in 1994 due to lack of funding. Chaos reigns as a few days earlier, hundreds of copies of the 2nd Announcement had been distributed by member countries to all their members! For the next three months, the UK Secretariat and IPWSO are bombarded by letters and faxes. UK passes over all documentation and enquiries to us. The Board finally takes the decision to postpone the conference until 1995 and **Norway** comes to our rescue by offering to host it.

I'm invited by the **Finnish** newly-formed PWS Association to participate in various meetings with their members and with representatives from their Mentally Handicapped Association. Their Chairman, Kimmo Salminen and family hosted me in Helsinki in temperatures of -25 C. The meeting was held the next day in Tampere, home of **Tiina Silvast** who was to replace Kimmo as Chairperson. There it was -35C!

When in the south of France - the seat of the French PWS Association - I tried, in vain to make contact with both the professional and parent delegates who failed to answer all

correspondence or pay their dues. I even met with a PWS family there who had no knowledge of the existence of Willi Prader Association and thought PWS was a virus!

1994

While participating in PWSA-UK's Annual Conference, a meeting is held with **Sheldon (Shelley) Tarakan, Publisher of Perspectives**, the US Quarterly Journal of PWS Information for Parents & Professionals. He agrees to publish an article on IPWSO in his journal and various other ways of collaboration are discussed. None of these materialise.

PWSA-Spain is formed.

After years of corresponding with **Poland**, my business takes me there. **Dr. Ewa Obersztyn** gathers some 40 families from all over Poland, together with some of her colleagues interested in PWS, and invites me to her hospital to meet with them. I meet again **Alicja Borek** and **Elzbieta Drozdowska** who'd attended our IPWSO conference in The Netherlands. The interpreter has a really tough time as questions tumble over one another! The warmth and engagement emanating from this meeting is indescribable. How much we need each other to share our strengths, tears and laughter!

PWSA-Poland is formed.

First meeting of PWS Nordic Parents is held in Stockholm funded by the Nordic Committee on Disability.

Representatives from **Denmark, Finland, Greenland, Norway and Sweden** participate. It is decided that meetings should be held every second year. Since our social systems are so similar, we can benefit by keeping in touch with PWS developments in our

neighbouring countries. **Greenland**

becomes an Associate member of IPWSO. Leif Peterson, who is a teacher, has two Eskimo pupils with PWS.



*1st Nordic Parent Meeting - Stockholm 1994
Participants from Norway, Denmark, Finland Sweden and Greenland*

The long-awaited IPWSO's Newsletter for Professionals is published. It is edited by **Dr. Ellie Smith (AUS)** This first edition includes articles by Susie Cassidy on Investigation of Thermoregulatory Characteristics in Patients with PWS; by Vanja Holm on Postnatal-Onset Obesity Syndromes, and by **Ellie** herself on Atypical PWS Cases.



*Norwegian Planning meeting for the 2nd International PWS Conference held in Oslo 15-18 June, 1995
Bjorn Lofferod, Jon Haugervåg, JPM, Arvid Heiberg, Anna Lisa Haanaes, Christian Aashamar*

Many trips to Norway to help with the planning of the 1995 Conference. The First Announcement goes out in April. **Christian Aashamar** (Frambu Helsecenter) chairs the Conference Organisation and **Dr. Arvid Heiberg** (Frambu Helsecenter), chairs The Scientific Programme. **Susie Cassidy and Martin Ritzén** recommend speakers for the Scientific Programme and letters are written.

Again the time-consuming problem is funding. This is discussed at length in many of our faxed Board Meetings. It is pointed out that more and more countries are starting **Associations for Rare Disorders** and many of our national PWS Associations are members. Although we have little in common so far as the handicap goes, we do share the same problems of being recognised and of being funded. Is an affiliation with some such an organisation the future for IPWSO maybe?

After 32 years I leave Sweden and return with my husband Sven to the UK, leaving our son, Anders, in the Swedish PWS group home. Despite this move, **RBU** agree, after lengthy negotiations, to continue their **annual support to IPWSO of \$5,000 during my Presidency.**

1995

Still very involved with preparations in Norway. Funding is organised. **Susie Cassidy, Martin Ritzén and Susanne Blichfeldt** join us in Frambu to help finalise the programmes and go through all the Abstracts.

Much work is done on all the papers to be presented at our first GA. Some amendments to the original Statutes which had been sent by mail and approved by Member countries, are faxed backwards and forwards between Board members.

Mildred Lacy (USA) replaces **Janalee Heinemann (USA)** on the Board. **Jackie Waters (UK)** replaces **Julien Courtauld (UK)** and offers to become Secretary. **At last IPWSO has a Secretary!** I write to **Giorgio Fornasier (Italy)** and **Mariano Riestra (Spain)** asking them if they would like to put their names forward for nomination as

we need some Latin blood to mix with all these Anglo-Saxons on this Board.

Mariano agrees to become **Treasurer** and **Giorgio** agrees to sing at our conference! We inform them of the interest shown by **Argentina**, which means

we could soon **open up the Spanish-speaking Latin American** continent for PWS with their help.

PWSA-Switzerland express the need to motivate their members to be more active and invite **Dr. Prader** and myself to address a gathering of their professional and parent members. While there, Esther Könz, President takes me to a clinic where four PWS patients follow a strict diet where they are fed every hour! I pass some wonderful days with the Könz family in their lovely home outside Zurich.

The IPWSO brochure is finally published in time for the Conference. **Spain and the USA** put in their bids to host the 1998 conference and will give their presentations at the General Assembly.

On 15-18 June **The 2nd PWS International Scientific Workshop and Conference** is held at **Sormaarka, Oslo**, sponsored by **Eli Lilly (Norway), Pharmacia Kabi Peptide Hormones (Sweden), RBU (Sweden) and the Norwegian Department for Health and Social Welfare.**



PWSA-Switzerland's National Conference. Esther Könz, founder of PWSA Switzerland, presents Dr Prader with flowers



Time for Sight-Seeing!

Mildred Lacy (USA), Linda Thornton and Cindy Adams-Vining (NZ)

Argentina, Israel and Kenya are represented for the first time .

Despite floods and air strikes, 225 delegates from 24 countries turn up. The Norwegian organisers certainly deserve the IPWSO commemoration plaque they are awarded, as their phones never stop ringing. The news of cancelled flights and floods had been broadcast world-wide and delegates were panicking.

65 participants had to be re-routed at the last minute! Once again, **Dr. Prader accepts to give the opening talk.**

Compared with the conference held in Holland four years ago, this was filled with optimism. With good management, people with PWS are now believed to live to a



The Dutch Delegation to Oslo, Wildred de Ley, Paul Willens, Piet van Oosten and Henk Moezelaar

normal age, not become too obese and to have a reasonable quality of life. Much work continues to be done on mapping the chromosome deletion and on the management of PWS behaviour.

Many presentations were made on the effects of GH treatment in children. These took up the body size, body composition and also the

effects on behaviour. A randomised controlled study of GH treatment on 27 children with PWS could undisputably show that in most children with PWS, GH treatment is beneficial. Until then, the positive effects of GH in PWS had been questioned by many scientists.

Ongoing studies were presented of the different symptoms and side-effects of drugs. For the first time it was shown that the mid-brain (hypothalamus) of persons with PWS had a lower than normal number of nerve cells containing a hormone (Oxytocin) involved in reproduction, mood, appetite and others. Later other nerve cells in this area of the brain have also been shown to be abnormal. The very sensitive issue of how to bring to the attention of parents **the need to have PWS brains** from the deceased for research is discussed. (Several countries launch the idea in their newsletters).

The “new” problems of adulthood and aging in PWS give us all food for thought and the various types of living arrangements are presented. In **Northern Europe**, the homogenous PWS group-home, or mixed handicap group-homes, are most favoured. However, in the **Latin countries**, most parents like to keep their offspring at home within the family.

At the General Assembly it is decided that the Scientific Newsletter should be incorporated into **Wavelength**. Distribution problems are discussed. The amendments to our **Statutes are unanimously approved regarding the limit to Board members' mandates**. However, the GA approved that Linda Thornton and my mandates should run for another 3 years, instead of the 2 yrs. recommended, to coincide with next international conference. Sven Martinsson (SWE) is elected nominations officer.

The Board is constituted as follows:

Jean Phillips-Martinsson **(SWE/UK) President**

Mildred Lacy **(UK) Vice-President**

Mariano Riestra **(SP)Treasurer**

Linda Thornton **(NZ)Wavelength**

Jackie Waters **(UK)Secretary**

Giorgio Fornasier **(Italy)**

Susie Cassidy (USA) and Ellie Smith (AUS) are co-opted to the Board as Scientific Advisors.

Spain wins its bid to host the next 1998 International PWS Conference after an excellent presentation. A wonderful evening of Norwegian folk dancing is enjoyed by participants. Giorgio Fornasier (ITL) and Dr. David Graham (NZ) share the guitar this time and sing for us.

Argentina and Kenya, who are represented for the first time, become Associate members, as does **Japan**.

The first edition of the Scientific Newsletter, incorporated into Wavelength, is published.



Norwegian Folk Dance at Sormarka. Andreas Prader studies the steps!

1996

Following the conference in Norway, there is a notable increase in correspondence and phone-calls from parents asking IPWSO for advice. Mildred Lacy (USA) offers to add information about IPWSO to PWSA-USA's own homepage, listing contact-names and providing information.

PWSA-Israel is formed.

At Ellie Smith's recommendation, I'm contacted by Audrey Angelman of the **Angelman Syndrome Association**. She is anxious to build an **International ASA**, based on the formation and work of **IPWSO**. Documentation and advice are provided over many months and we agree to collaborate and exchange ideas.

The Spanish organisers are provided with all background documentation from previous conferences. However, they worry about the lack of professional PWS competence in Spain to Chair the IPWSO conference and ask IPWSO to recommend one of its professional members to take over. Our Scientific advisor, **Ellie Smith, (AUS)** agrees to become Conference and Scientific Programme Chair. Once again, **Susie Cassidy (USA)** acts as Scientific advisor and recommends names of speakers.

Jackie Waters and Margaret Gellatly (UK) agree to Co-chair the Professional and Parents' Programme.



Sipping Champagne Donated by the Spanish Embassy at Sormarka Conference Centre, Andreas Prader and JPM

Mariano Riestra, President of PWSA-Spain and newly-appointed IPWSO Treasurer, and his wife visit our home in the UK and meet up with Julien Courtauld (UK) who passes over all the accounts. **A Spanish bank account is opened for IPWSO in Madrid**. On request, our Statutes and Charity Registration are issued with a Spanish stamp, as required by the Spanish authorities.

PWSA-France is resurrected by Jean-Yves Belliard, who had attended our first conference, and by **Nicolette Ponsart**. It is re-baptized Prader-Willi France and goes from

strength to strength. In the same post we learn that **PWSA-Japan** has been formed.

Ellie Smith (AUS) represents **IPWSO** at the **European Society for Human Genetics Conference in Helsinki**. On the way, she drops off in Sweden and spends two days with us in our log cabin. Most of the time is spent admiring the 1st Announcement sent from Spain and drafting further documentation. We do find time to relax together too - bathing, boating and cycling!

Linda Thornton (NZ) invites me to present at the **6th Australasian PWS**

Conference in Auckland 1-3 November. I give one talk on IPWSO and the other on Residential Care in Sweden. Afterwards, my husband Sven and I spend 3 relaxing days with Linda Thornton and her family. On the way to NZ, we stop off Down Under. There Ellie Smith organises for me to give presentations at the various PWS regional offices in **Adelaide, Melbourne and Sydney**. In Adelaide, two meetings are held with the **Intellectual Disability Services Council** to inform them about the setting up and success of PWS group homes around the world. In **Sydney, Judith Gelb (AUS)**, parent delegate, gives a reception for us and we visit a PWS home where her daughter resides. One week is spent in Sydney, where both **Dr. Verne Caradus** and **Ellie Smith** host us. Ellie invites us to visit her Cytogenetics Dept. at the New Children's Hospital where they peer down microscopes studying Mum and Dad's chromosomes! On the return journey, we stop over in LA and have dinner with **Fran Moss, co-ordinator of the California PWS Foundation**, her husband and daughter.

This is the year of the e-mail and Internet! Almost all Board members invest in email and can now surf the net. But IPWSO still needs its own website and few of us have the competence to do this. On recommendation by the Board, **Linda** takes up contacts once again with **Shelly Tarakan, publisher of PWS-Perspectives who agrees to host a web-site for us. Information on IPWSO, including lists of member countries' delegates, is now available on www.pwsyndrome.com.** at the flick of a button. In future, all those "new" families and professionals need no longer feel isolated. The worldwide web will keep them updated with the latest developments and put them in touch with those with the "PWS know-how".

1997

The organisation of the **3rd PWS International Conference to be held in Seville, Spain**, involves IPWSO in a great deal of work and expense during this period. But, after two years of supportive work from Committee and Board members, the conference is cancelled on 10th May, 1997 at the 1st Board meeting of the Spanish National Association Conference held in Valencia. The fact is that, with only one year to go, no funding has been obtained, no hotel has been booked nor have prices been negotiated.



Spanish Doctors Briefing Meeting 1996 Ellie Smith (Aus), Jaime Campos Castello and team

Leading up to that date, **Giorgio Fornasier and I met with Mariano Riestra in Madrid** and participated in several fund-raising meetings with authorities. We also met with IPWSO's Bank Manager in Madrid and discovered that very few countries had paid their dues! Dr. Ellie Smith and I gave presentations at the Spanish PWS National Congress in **Valencia** and met with various members of **PWSA-Spain**. Following that, we flew to **Seville** where we were joined by **Margaret Gellatly** to check on conference facilities. It was during this stay that we received the cancellation phone-call!

With this experience, the “**Guidelines for Hosting IPWSO Conferences**” have been revised. Countries who put forward their names to host conferences must be aware that it's hard work. **Funding, the full support of their members and a strong team who can pull together, is essential to the successful running of the conference. IPWSO's Scientific Advisors are available to them so far as**



Italian Doctors Briefing Meeting 1997. Guiseppe Chumello and team

input is concerned.

In June, **Giorgio Fornasier** comes with the fantastic news that the **PWSA-Italy** are willing to take over from the Spanish, provided that they can postpone the conference by one week!

IPWSO's Bank Account is transferred from Spain to Italy and Giorgio attempts to collect member countries' dues. Giorgio pays us a visit in the UK, together with 17 Italian clients! We hire a mini-bus and take them on a sight-seeing pub crawl.

In September, I am invited to St Raphael Hospital in Milan to meet with the conference team of doctors and parents led by Prof. Chiumello. Dr. Laura Bosio is co-opted to the Conference team as co-ordinator. We also meet

Target Motivation, the contracted conference organisers, finalise some details and visit the Conference site.

Udo Robmanneck, Chairman of PWSA-Germany, invites me to participate in their National PWS Conference in Dusseldorf to talk about IPWSO and promote the 1998 Conference to be held in Italy. There are 296 participants including **Dr. Verena Wanker Gutmann (Austria), who went on to found the Austrian PWS Association**. Afterwards, Anette Wetzel and her family invite me to spend some

days with them in Leipzig - **in the former Eastern zone of Germany where PWS is still little-known**. Before travelling, Martin Ritzén had given me the name of one of his colleagues there - **Dr. Keller at the Leipzig Children's Hospital**. We have a 2-hour meeting with him when he agrees to organise a PWS seminar for his colleagues from the former East Germany.

In my thank-you letter to the Germans, I suggest that, with such a large Association of some 400 members, they may like to take a more active role in IPWSO and nominate a candidate to the Board. A few weeks later, they nominate **Monika Fuhrmann** whom I discover is a professional soprano. I suggest she gets her act together with Giorgio at the next conference. Not bad to have 2 professional singers in our Board of 6 members!

An IPWSO Logo competition is launched. Member countries are encouraged to come up with ideas.

More contacts with **Shelly Tarakan**. He has offered to take over the editing, publishing and distribution of Wavelength, and the production of our IPWSO brochure. Unfortunately, **negotiations break down and IPWSO no longer has a www page.**

1998

Margaret Gellatly (UK) is invited over to the Lido to help co-ordinate the programme and see the facilities.

A meeting with **Verena Wanker Gutmann (Austria)**, her husband and daughter is arranged at Salzburg Airport on our return from a skiing vacation. We spend an enjoyable afternoon between flights at home with her family and discuss further her ideas of founding an Austrian PWS Association. Some months later **PWSA-Austria is formed.**

IPWSO becomes a member of The European Disability Forum (EDF). This year they have initiated a Rare Disorders Group which we have joined, together with 6 other handicap groups.

3rd PWS International Scientific Workshop and Conference, Lido di Jesolo, Italy, 21- 24 May, was attended by some 250 delegates from 24 countries. One new country, **Malaysia**, is represented. Once again, **Pharmacia & Upjohn**, (Sweden) sponsor us, as do the **Pediatric Clinic of St. Raffaele Hospital**, (Italy) and some local Italian companies.

Among highlights from the Scientific Programme are several presentations relating to further investigations into the clinical and medical aspects of PWS. One study into

58 patients with PWS, confirmed by molecular testing, indicated that fully half of all patients either lacked one or more of the major criteria or had some extra findings.

An animal model for PWS was presented - a mouse strain that had genetic abnormalities similar to those in PWS. This is an important tool when it comes to developing drugs that alleviate the symptoms of PWS.

A few studies mentioned small differences between patients with deletion and uniparental disomy as causes of PWS, most of which suggested that disomy was harder to diagnose and the patients were less likely to have lethargy. Again, the news on growth hormone treatment in PWS received great attention.

Health care guidelines for people of all ages with PWS were developed by the Scientific



*GA at 3rd International Conference Held in Italy 21-24 June, 1998
Leopold Curfs (NL), Susie Cassidy (USA), Cindyn Adams (NZ), Jo
Gibbons (NZ), Bernard Horsthempke (D), Nicolette Ponsard (Fr)*

Advisory Board of the PWSA (USA). Management of PWS requires a multidisciplinary approach to delivery of care nutritional, medical and behavioural. These guidelines include suggestions for managing concurrent medical, developmental, behavioural, educational and social issues - addressed from the neonatal period through adulthood. They are designed to be a resource to health care providers, authorities and all who all care for persons with PWS.

From the parents' point of view, Jackie Waters (UK), mother of a daughter with PWS, sums it up like this: The message that came through loud and clear is that there is still no magic bullet, but our understanding of the great complexities of PWS is getting better. I was fascinated to hear that there can be as many as 20 different factors affecting appetite. Three recommendations stand out in her memory:

1) The request that everyone should offer to participate in research and that people should think very seriously about the difficult subject of donating brains.

2) Longitudinal research. This type of research studies a number of individuals and families over a number of years, rather than looking at them in one moment of time.

3) The need for an appropriate ethical and legal framework which is quite specific to the needs of people with PWS.

At the official opening, there is some tragic news. Birgit Schroeder, (SA) a member of the Board who had been with us from the start and had planned to attend the conference, had died suddenly. A minute's silence was held.

Since Linda Thornton and my mandates have expired our names cannot be put forward for re-election. At the General Assembly, 4 new nominees are all elected to the Board and Giorgio Fornasier is elected President:-

Giorgio Fornasier (Italy)	President
Mildred Lacy (USA)	Vice-President
Monika Fuhrmann (Ger)	Secretary
Cindy Adams-Vining (NZ)	Wavelength
David Gordon (SA)	Treasurer
Susanne Blichfeldt (Den)	Scientific Co-ordinator

Due to pressure of work, **Susie Cassidy (USA)** steps down as Scientific Advisor coopted to the Board, and is replaced by **Martin Ritzén (Sweden)**. **Ellie Smith (AUS)** is re-elected.

Susanne Blichfeldt (DEN) agrees to take over the Scientific Newsletter and **Cindy Adams-Vining (NZ)** the parents and professionals section of Wavelength.

PWSA-Australia and PWS-USA apply to host the 2001 conference and give their presentations. **PWSA-USA** wins the vote and the next conference will be held in **Minnesota 27th June - 1st July, 2001, the year of IPWSO's 10th anniversary.**



IPWSO at last has it's logo! Eight countries participated in this competition but the GA voted for the one designed by **Tiina Silvast, Chairman of**

the Finnish PWS Association and a graphic designer herself. The design is of a golden heart, a symbol of goodness and caring, with a leaf to depict possibilities. Isn't that, Tiina asks, what IPWSO means to all people with PWS and their families all over the world - the possibility of a good life?

Giorgio Fornasier takes over as President. As founder of IPWSO and President since it's formation, Jean is presented with a gold medal and certificate of appreciation signed by all 22 member countries; "Without you Jean, we'd not be here!"



The Italians organise a beautiful closing banquet where Giorgio Fornasier and Monika Fuhrmann sing their duet. Giorgio presents me with a wonderful certificate of appreciation, signed by all member countries and a gold medal. On them is written: "Without you Jean we would not be here".

These 15 years have been hard work but they have given me so much. They've been exciting, frustrating, emotional, but enormously rewarding. The thrill experienced when new countries form their own PWS Associations and join our IPWSO family is worth all the hard work and late nights! I've learned so much and made so many new friends throughout the world that I would encourage all parents who share our goals to become active members of IPWSO.

Let me end this short history by reminding you of IPWSO's goals. They aim to:

- **improve the quality of life for all people with Prader-Willi Syndrome and their families**
- **improve the physical and mental well-being, socially as well as occupationally, of all people with PWS, so that they may, according to their wishes and abilities, lead a life as normal as possible**

IPWSO will meet these goals by:

- **stimulating international collaboration on PWS research projects on the origins, management and prevention of PWS**
- **encouraging national associations to exchange and share their PWS projects and experiences**
- **fostering the foundation and development of new national PWS Associations**
- **encouraging the international exchange of people with PWS and of those involved with their care**