
In tribute to Jean Phillips-Martinsson

Messages of condolence and remembrance

I was saddened to hear about the passing of Jean, it seems she'd always be around the PWS world whether in the UK, Europe or other international settings. I started working with adults with PWS in 1986 and Jean was a person I clearly recall when attending conferences, always ready to talk and share her knowledge and expertise. A passionate loving mother to Anders but as passionate and as informed a mother about PWS that I've ever had the privilege to listen to, and this was long before the internet became so ubiquitous. Whether presenting, moderating or just contributing, she had the audience in the palm of her hand. Jean will be missed by all who knew her.

- Myles Kelly



Jean Phillips-Martinsson (in the white jacket) pictured with Professor Andrea Prader and Professor Martin Ritzen at the 2nd IPWSO International Conference in Oslo, Norway, in 1995. Also pictured are Arvid Heiberg, medical leader of the Frambu Centre in Oslo, and psychologist Britta Bøhm, both from Scandinavia, alongside two doctors from Spain.

Jean was such a happy and encouraging lady. I remember first meeting her in Oslo, the 2nd IPWSO meeting, and being in awe of her strength, enthusiasm and commitment to all things PWS. I had the pleasure of

meeting her many times and she will always be warmly remembered and with a her broad smile...

- Georgina Loughnan

I was deeply saddened to learn that Jean had passed. Her contribution to IPWSO and PWS was extraordinary.

I first came across Jean at an early PWSA UK conference in York in the late 1980s. In a plenary session about growth hormone, she argued with our then President, Dr Bernard Lurance, that growth hormone was essential for people with PWS, in contradiction to his own views that it was not. Even then I was amazed at her temerity in disputing what was then, in the UK, the perceived medical wisdom. She, of course, was in contact with early pioneers of the treatment in Sweden, and probably knew more than he did!

That awareness that many parents knew more than professionals would lead to her advocating for an international organisation where parents and professionals would work and learn together. She set up IPWSO as a charity in Sweden (now moved to the UK) and was tireless, along with others from various countries, in promoting international conferences to spread knowledge about the management and treatment of PWS. This before the days of the internet. As IPWSO Board Secretary when she was Chair, I received many long faxes and telephone calls from her.

Others will know more about her work in Sweden, helping to set up what I believe was the first PWS specific group home in the world - a model which has been acknowledged and adopted by many other countries who followed suit.

Her contribution to the world of PWS, and indeed the PWS family, cannot be underestimated. She was such a driving force - her determination, commitment and enthusiasm has led IPWSO to the wonderful organisation it is today. All of us who are living with those with PWS owe her immense gratitude.

- Jackie Gill, PWSA UK

It is with great sadness that the African Society of Pediatric and Adolescent Endocrinology (ASPAE) has learned of the passing of Jean Phillips-Martinsson. On behalf of ASPAE, we extend our deepest and most sincere condolences to his family, loved ones, colleagues, and all those who had the privilege of knowing her.

During this difficult time, our thoughts and prayers are with the bereaved family. May God grant you strength, comfort, and peace as you go through this painful Loss.

May the memory of Jean Phillips-Martinsson remain a source of comfort to all who knew and loved her. Our heartfelt condolence to the entire family. May her soul rest in eternal peace.

- Adele Chetcha, ASPAE acting President

I am so very sorry to hear of Jean's passing. She really was an absolute legend in the PWS community - a true force of nature and such a remarkable person.

I feel very lucky to have spent some time with Jean and Anders (when he visited Jean in the UK) and I will always remember and admire her extraordinary drive, energy, strength, tenacity and humour.

She had such a sharp mind, tremendous vision and determination, and an incredible ability to make things happen.

She achieved so much, and the impact she had on the PWS community was enormous. She was truly pivotal in helping shape and strengthen it over so many years.

Jean will never be forgotten. Thank you, Jean, for simply being you, for everything you gave, and for everything you have done for so many people within the PWS community.

Reunited now with Anders and Sven.

- Jane and Marina Hicks,

I'm so sorry I am not able to come to the Celebration of Jean's life, because what a celebration it will be! There is so much to celebrate about Jean: she was an extraordinary woman, with an extraordinary drive to meet challenges head on, and, in doing so, change the world for the better for so many people, not least those of us living with Prader-Willi syndrome. From the bottom of my heart, thank you Jean - we will never forget you!

- Jackie Gill (Waters)

I was very honoured to work with Jean during my time at IPWSO, as well as spend time with her during the 2022 International Conference. She was a fierce advocate for families around the world and her energy and passion for knowledge exchange and global solidarity around PWS was absolutely inspirational – Agnes Høctor

When her son Anders was diagnosed with PWS, Jean began her long fight for a group home for PWS in Stockholm, Sweden.

By bringing together five families, all with adult children with PWS, living in the Stockholm area, they decided to fight together for their then adult children to be able to live in a group home together, with a focus on PWS. It took years and many negotiations before the then county council gave the go-ahead to build the group home.

In 1992, the group home opened in Stockholm.

I was one of the first to be hired and neither I nor the other staff knew anything about PWS. We received a thorough training of medical expertise, where the now deceased Professor Martin Ritzen at KS was Sweden's leading expert. Later, with Dr. Charlotte Højbye, she became our main source of medical knowledge. But the most tangible expertise was of course the parents and the most driving force of all was Jean. Jean was strong, combative, knowledgeable and stubborn. As a staff group, we could not always meet her wishes or demands. But she became an engine for us. We would not give up, we would become, not only the first group home for PWS in Sweden, but we would also be the best and the most knowledgeable. I dare say that we were.

Without Jean and without parental cooperation, it would not have been possible.

Jean and her husband Sven were founders of the Swedish PWS association in 1986, which first gathered relatives, but eventually also staff. For about 10 years, I had the privilege of being chairman and we then began to organize seminars on PWS, where Jean was an obvious lecturer.

Jean had, throughout her life, a guiding star: her son Anders would have the very best conditions to live a good life. That made her commitment great, but her heart even bigger.

Jean was incredibly generous with her knowledge and experience.

When Anders passed away and a few years earlier her husband, her life was never the same. But the passion remained and the passion to draw the attention of the whole world to what PWS is.

For me, who has worked as the manager of the group home for 25 years, and for the staff group who worked there then, the memory of Jean will always live on.

The world would need many more of such a fighter.

- Lisa Boman, former manager of The Group Home

Gracias



Jean Phillips Martinsson



For the Mexican Prader Willi community, Jean was a pioneer and a true pillar. As the founder of IPWSO, she helped pave the way for a community that for many years was little understood and rarely heard.

Her vision and commitment left a lasting mark on Fundación María José, our families, and our entire community.

From Mexico, thank you, Jean, for believing in us and for opening paths that we continue to walk today.

