

# Ontario Prader-Willi Syndrome Association Report to Annual General Meeting



*Jenna Bouwkamp & Matthew Moldenhauer share romantic moment at a board meeting*

## October 2004-October 2005

The past year has been filled with a variety of programs and a feeling that we are moving forward and expanding our abilities. Our board has been re-energized by the active presence of several new younger members. We believe that when combined with the wisdom of those board members who have “been around the block”, we have a great combination for planning and expanding the role of OPWSA in the coming years.

Under the guidance of our part-time executive director, Nita Goldband and with the assistance of our office volunteer Danielle Hurlburt, our OPWSA office is able to sustain new growth. Office rental continues to be paid by K&G Construction until October 2006-resulting in great savings to OPWSA.

We had about 7 new families with infants contact OPWSA this year. This is higher than usual and may be a result of increased awareness.

In order to facilitate planning over the coming years, the board will be engaging in a strategic plan over the next few months. We would welcome input from all of our membership as to your “visions” for OPWSA.

### **OPWSA Programs & Services**

#### **Advocacy & Support**

OPWSA receives numerous requests for information every day by e-mail, phone and letter from all over the country. All are responded to in a timely way. If there is a need for a case conference meeting or education package to be delivered, Nita Goldband, our executive director attends and provides follow up as required. Beginning in 2003, all new members receive one year free membership to OPWSA, a parent handbook and other informative materials-as well as access to a parent buddy. This past July at the PWSA-USA conference we received PWS information packets developed by the International Prader-Willi Syndrome Association. These will be added to our new members packets in the future.

The following letter speaks to how important the support role of OPWSA can be:

*“Hi Nita, We are all so happy. For six years we have been tip toeing around \_\_\_’s o.c.d. behaviours. It’s like being able to breathe fresh air again. Thank you so much for your support and for setting me on the right path. I feel as though our family has been saved—we were at our breaking point as you know. I just cannot express what your help and understanding meant to us all. Thank-you”*

### **Education Workshops & Case Management**

On-site meetings this year took place at the Toronto Association for Community Living-Day Workshop, York South Association, Community Living Burlington and Community Living Dufferin.

### **Research**

In an effort to expand OPWSA activities in promoting scientific research, a committee was formed this year with Dr. Glenn Berall acting in an advisory capacity. The first activity of the committee was to compile a research scan for the past two-three years. This document will be kept up to date and available for membership upon request. A request was received from Dr. Berall for the funding of a part-time research assistant to complete documentation for the publication of the R.Y.G studies undertaken by the clinic as well as initiating a project on the efficacy of topirimate in the PWS population for appetite control. This has just recently been approved and \$22,000 will be allocated for this purpose.

### **Communications**

#### **Website**

Thanks to the excellent capabilities of Jennifer Gignac, our website has been updated and now provides us with a useful communication tool. Jennifer has agreed to act as our webmaster and keep the site updated and add to it as necessary. Membership forms, conference registration, resource lists and medical bulletins as well as other documents are available and updated on a regular basis.

#### **Newsletter**

Robyn Heaton has taken on the job formatting and editing the newsletter. Because she is producing it in a pdf format, it can be e-mailed to members as well as posted on the website.

### **Publications**

#### **Red-Yellow-Green Booklet**

The RYG program is used exclusively in the PWS Clinic at the North York General Hospital with great success. It has also been the program of choice used at the Pittsburgh In-patient PWS Clinic. In order to increase the accessibility of the diet, Karen Balko, Dietitian and a dedicated committee undertook an update of the existing materials, incorporating tips on food management, recipes, exercises, etc. The book was completed just prior to Conference 2005 and is currently available for sale on our publications list.

#### **Exercise Booklet**

Rob Pividor, exercise therapist is the designer of this work in progress which will hope will provide a handy guide to developing an exercise program for people with PWS. Expected publication will be in 2006.

#### **New Parent Handbook**

This booklet which was published three years ago and has been well received will be updated and expanded to include additional materials as well as a notebook to be used for recording information. Expected publication will be in 2006.

## **Conference**

Conference 2004 was a great success-attracting over 150 people as well as 40 children and young adults who participated separately in a fun-filled day of activities including a trip to the Ontario Science Center and a very successful Yoga Class. Highlights of the educational program included a presentation by Dr. Berall on the Canadian Paediatric Surveillance Program and on Sleep Apnea, a presentation on Dental Issues in PWS from Dr. David Farkouh. The afternoon workshops included: Planning for the Future with Elaine Atchison, from the Ministry of the Attorney General and a session for Care Providers from Mary Ziccardi-a specialist in PWS from Ohio.

## **Canadian Paediatric Surveillance Program**

The CPSP program has been completed and a final report will be published in the Canadian Paediatric Journal. Dr. Glenn Berall was the medical coordinator of the study and OPWSA is a funding partner in this program-along with CIBC. The program was Canada wide and consisted of a two year survey distributed monthly to 2300 physicians. The survey gives a clearer idea of incidence of PWS as well as the prevalence of medical conditions. The numbers of new cases identified was lower than expected.

## **Prader-Willi Residential Developments**

The group home at Vita has now been open for a full year and all residents are doing very well. Most have lost at least 20 lbs. A respite bed has been made available on a per diem basis and is being used successfully.

A group home with “a food safe environment” under the auspices of Dufferin Association for Community Living has also been opened in the past month. Currently it serves one young man but it is hoped that there are others in the community that will be able to live there. OPWSA provided an extensive training program for the staff. over the summer.

## **Fundraising**

### **Bids and Bites**

Under the new leadership of Ana Snjaric and her committee, the 7<sup>th</sup> annual Silent Auction and Lunch raised over \$10,000. This annual event is more popular every year and was moved to the Markland Woods Golf & Country Club-a larger venue as the hotel space previously used was becoming cramped. This year-gift bags were handed out to our attendees.

### **Walkathon-One Small Step**

Under the enthusiastic leadership of Keegan & Tanya Johnson, this event which took place at Centennial Park in Etobicoke on Sunday August 25th was an incredible success. Over 250 people participated, \$50,000 was raised and in addition to the walk-a variety of activities were available. CIBC was a major sponsor for this event- our thanks to them. It is planned that this event will be repeated in the spring/early summer of 2006.

### **Holiday Campaign**

OPWSA runs this direct mail campaign annually in November. Along with an informative newsletter for our donors, we also offer an opportunity to make a donation and send a holiday greeting to the recipient of choice. The campaign raised \$5500 this year.

### **Light up the Night**

This special evening took place in April 2005-and honoured Dr. Glenn Berall who has run the PWS Clinic at North York General Hospital for over 10 years. A special booklet was prepared for

the evening and printed courtesy of Ingrid Buchner and Windsor Media. Lindsay Bouwkamp and Jen Gignac prepared a moving powerpoint tribute and Lisa Newbigging spoke about her personal experiences and successes with the clinic. Flashlights were donated by Energizer Canada to "Light up the Night." 125 people attended and over \$26,000 was raised. From the funds, \$10,000 was donated to the clinic to purchase a body mass index machine and to purchase new materials required for the patients of the nutrition clinic for PWS.

### **Swimathon**

The Swimathon program provides an opportunity for those individuals with PWS to raise funds for OPWSA by collecting donations and participating in a swim on the day of our annual conference. This program raised over \$5,000 in 2004 and each participant received a certificate of accomplishment and a coupon from Rogers Video.

### **Garage Sale**

Coordinated by Mike & Heather Kestenbaum, the Toronto garage sale has become an OPWSA tradition heralding the spring and a great opportunity to clean out our closets. This year's sale raised over \$700 for OPWSA. Thanks to Mike & Heather for their ongoing efforts.