

# Global Pituitary Patient Advocacy Meeting

October 19–21, 2012 • Zurich, Switzerland

**With 24 pituitary patient advocates from 18 countries, the first Global Pituitary Patient Advocacy Meeting was a success. The meeting led to a commitment to work together and the drafting of the *Zurich Declaration*, which identifies a set of basic standards for pituitary disorders and calls upon healthcare professionals, hospital administrators and health authorities to adopt them for the benefit of the patients they serve.**

## EXECUTIVE SUMMARY

Twenty-four pituitary patient advocates from 18 countries attended the first Global Pituitary Patient Advocacy Meeting in Zurich, Switzerland, from October 19–21, 2012. The meeting was sponsored by Novartis and the agenda was developed in consultation with patient advocates from three countries.

Disorders arising from pituitary tumors are rare, and pituitary patient advocates and patient advocacy groups (PAGs) may have difficulty finding support, obtaining experience, and developing an efficient network locally. The objectives of the meeting were to enable Cushing's disease, acromegaly and pituitary patient groups to:

- Identify and address common challenges faced by their patient communities
- Share best practices
- Receive updates on disease-related topics

To meet these needs, the 2-day meeting included sessions on fundraising, working with the media, working with industry, collaborating across regions, and disease updates. The meeting succeeded in achieving the above objectives and culminated in a commitment to work together globally through the drafting of the Zurich Declaration.

This brief report provides a summary of the educational sessions.

## BEST PRACTICE SHARING

A morning **working session was held** in which each table discussed the challenges and possible solutions to working with the media, healthcare providers and pharmaceutical companies, as well as fundraising. A common theme was the challenge of raising awareness and funds as pituitary disorders are very rare.

During this session, advocates from Argentina, Australia, Russia and Chile shared examples of their best practices in pituitary patient advocacy.

- The **Argentinean PAG (APEHI)** has created a guide to help pituitary disorder groups throughout Latin American develop and become successful. In collaboration with groups from Brazil, Chile, Colombia, Mexico and Venezuela, they have developed a 'cookbook' covering best practice in areas such as leadership, starting up, looking for potential sponsors, raising awareness, dealing with the media, and fundraising.
- The **Australian Pituitary Foundation** has developed a series of booklets for patients, written in a patient-to-patient tone, explaining what tests are performed in the diagnosis of pituitary diseases, why they are performed, and what to expect from the results. These booklets were created to ease the fear patients often experience at the time of diagnosis, and share the personal experience of pituitary patients to provide understanding and hope.
- In **Russia**, 'rare diseases' are a new disease category recognized on January 1<sup>st</sup> 2012, which creates certain legal challenges and requires a trailblazing approach as few processes are well established. In this setting, the pituitary advocacy group **Velikan** was founded in January 2012. To date, the group has been very successful in liaising with officials and helping some patients gain access to high-quality therapies.
- In **Chile**, formation of the **Patients Association of Tumors and Diseases of the Pituitary (APTEH)** is still under way, with the main priorities being contacting other patients, establishing the goals and bylaws of the group, and finalizing its training process.

- The founder and president of the **Swiss Support Group for Pituitary Gland Diseases** has had many years of experience with a successful pituitary PAGs and shared his list of Dos and Don'ts. All of the attending patient advocates requested a copy of these, and they are listed below.

## **Dos**

- If you found and lead a self-help group, be aware that it is work-intensive, that you need time, assertiveness, negotiation skills and nerves right from the beginning
- Use a binding legal form for your PAG to simplify things
- Use a fixed organizational set-up and define clear responsibilities and duties
- Whenever possible, delegate repetitive administrative tasks. The leader needs to be the mastermind, organizer and driving force
- Secure sufficient funds; a successful self-help group needs money
- Take the effort to win several different sponsors. With only one dedicated sponsor, you will be suspected of dependency
- Define clear objectives for your self-help group
- Join relevant umbrella organizations (international: eg, Pro Raris, OrphanNet; Switzerland: eg, patienten.ch, Selbsthilfe Schweiz, Patientenkoalition)
- At the beginning, focus on your own group before taking over bigger tasks in umbrella organizations
- Inform specialists and medical departments about the existence of your self-help group. They will help you win new members by raising awareness of your group
- Ask for the support of specialists. Most of them will help you
- Be sensible about the needs of your members and listen to them
- Be aware that the needs and commitment of your members are diverse and that you are the leader of a 'consumer society'
- Offer your members time to exchange ideas, but secure the provision of professional information; a mere discussion group 'runs to death' soon
- Organize interesting and varied events. They may also include lectures or activities that are 'dissimilar'
- A web page is nowadays a must
- Provide your members the opportunity to ask questions, give feedback and place requests
- Ensure clean and current membership administration; lost members will never return
- Ensure communication in your members' usual language; this accounts especially for speeches and product-specific information

- It is mandatory to appoint a deputy who is fully aware of all running business activities
- If ever you have the chance to be present on televised medical talks, take it. It makes people aware of pituitary disorders and will bring new members to your support group

### **Don'ts**

- Do not expect too much from your members, especially in terms of engagement
- Do not presume the same dedication from your members. Do not ask for too much
- If you organize events, do not expect participation of all members; 20–30% is a good quota
- Never cancel an event because only a few members participate. If this happens a few times, this would be the end of the group
- Do not put too much financial pressure on your members. The number of members is more important than your financial situation
- Avoid too many medical and technical terms in informational materials and in speeches or lectures
- Avoid interrupting ongoing discussions among members
- Do not consider the support group as your 'property'. You need the members and the members need you

## ADVOCACY ISSUES

### **Access**

Prior to the meeting, all delegates were asked to complete a survey to gather information about key issues faced by patients with pituitary diseases. The results were presented during the meeting, and showed that in most countries misdiagnosis or late diagnosis is a problem. Additionally, the results revealed that patients have access concerns, and payment for treatment can be difficult. Opinion was divided on the level of satisfaction the patients felt about the care they receive in their country.

A representative from the University of Glasgow, Scotland, UK, gave a presentation about health technology assessment (HTA). HTA is used by many countries around the world to determine which treatments should be reimbursed by the government. Suggestions to help patient organizations secure a voice in the HTA process were shared, the most important being to use solid evidence and information, not 'distress', to provide the patient's perspective. For example, the speaker recommended translating the emotional response into factual statements that explain what the symptoms or side effects mean: ("Fatigue caused by existing treatments is so severe that I have to lie down and I can't look after my children/can't go to work"). Advocates can contact their local HTA agency and ask how to get involved or visit the [Health Technology Assessment International](http://www.htai.org/) website (<http://www.htai.org/>).

## **Awareness**

Representatives from Switzerland, the UK, Ireland, The Netherlands and Austria shared key learnings from their disease awareness experiences.

**Switzerland:** An article describing the changes faced by the founder of the **Swiss Support Group for Pituitary Gland Diseases** due to acromegaly was seen by the presenter of a Swiss television series who decided to make a program about the condition. The program prompted many telephone calls and subsequently a patient with acromegaly was diagnosed in a remote mountain village. The experience motivated the founding of a support group for pituitary diseases in Switzerland. The key learning was:

*Take advantage of opportunities that come your way to raise awareness of the disease and the patient group*

**The UK:** Each year, the **Pituitary Foundation** holds a Pituitary Awareness Month in the UK which aims to increase the awareness of pituitary conditions and to raise funds to help the Pituitary Foundation maintain its patient support services. The campaigns during Pituitary Awareness Month are implemented by local area support groups using posters, distributing fact sheets, manning awareness stands, holding fundraising events and writing to ambulance trusts, hospital accident and emergency units, and GPs. These activities have resulted in local radio interviews and press articles, discussions with local ambulance trusts, a rise in membership and increased donations from local support groups. This year's focus was on raising awareness among the ambulance service and accident and emergency wards about secondary adrenal insufficiency and diabetes insipidus in patients with pituitary disorders, both of which can become acute emergency situations. The key learning was:

*Develop multifaceted programs to create news*

**Ireland:** The **Irish branch of the Pituitary Foundation** is much smaller than the UK organization and has only a small number of volunteers, making national campaigns difficult. The Irish branch staged a 1-week campaign to raise awareness and promote early diagnosis, targeting general practitioners (GPs) and the public. The campaign achieved press attention in a number of leading Irish national newspapers as well as television

coverage. Key factors in the successful campaign were funds to secure the services of a PR consultant, support from pituitary experts and pharmaceutical companies, and having patients willing to tell their stories in the media. The key learning was:

*Use publicity expertise when possible, and leverage patient stories to get the attention of the media*

**The Netherlands:** The **Dutch Adrenal Society** had a goal to improve the information patients with rare diseases received from their GPs. They developed brochures for GPs and other healthcare professionals. The brochures contain an overview of the disease, management and treatment options, and complications of the disease. In order to widen the distribution, the **Dutch Adrenal Society** partnered with the Dutch Alliance for Rare Diseases and the National College of General Practitioners. Each brochure was authorized by medical experts and the National College of General Practitioners and is available in both print and downloadable versions. The key learning was:

*Partner with larger organizations to expand the reach of the patient group*

**Austria:** The **Cushing's Self-Help Group in Austria**, founded in 2005, is very small and lacks funds and volunteers. The group is finding it difficult to raise awareness and is struggling to have a voice. However, members perceived that participating in the Global Pituitary Patient Advocacy Meeting was like finding friends after being alone for years.

*Find creative ways to raise awareness as well as patience, time and help!*

## Outcomes and Future Initiatives

Feedback regarding the meeting was very positive, with many of the advocates expressing how exciting it was to meet other advocates, and they highlighted how important networking is to patient advocacy. This meeting allowed the advocates to connect with each other, but it also enabled them to explore future collaborations. Future initiatives the advocates discussed were:

- 1) A worldwide Pituitary Disease Awareness Day
- 2) Branding for a global pituitary patient group through the development of a logo or other recognizable element to help unify and amplify their efforts
- 3) The Zurich Declaration

## The Zurich Declaration

During the course of the meeting, common priorities were recognized. The patient advocate attendees set forth a collective call to all parties responsible for diagnosis, treatment and care of patients with pituitary disorders for a basic set of standards in the “Zurich Declaration”. Subsequently this declaration has been signed by the following patient groups in attendance and has been translated into German, Italian, Russian and Spanish.

Acromegaly Community; Ayuda Pacientes con Enfermedad Hipofisaria, Argentina; Australian Pituitary Foundation; Cushing’s Disease Support Group, Austria; The Association of the affected by acromegaly and pituitary disease in Bosnia and Herzegovina; Corporación de Ayuda a Pacientes con Enfermedad Hipofisaria (COAPHEI), Chile; Vivir Creciendo Foundation, Colombia; Netzwerk-Hypophysen- & Nebennierenerkrankungen, Germany; Kasuikai, Japan; Rarissimus, Portugal; Dutch Adrenal Society (NVACP), The Netherlands; Inter-regional public non-profit charity organization of patients “Velikan”, Russia; Asociación Española de Afectados por Acromegalia, Spain; Wegweiser, Switzerland; The Pituitary Foundation, UK.