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Ipopi Conference – Istanbul October 2010 (continued)

Discussions were also held to highlight the importance of data collection including PID registries and how this can be used to benefit PID patients and patient organisations. In order to lobby governments for funding, raise awareness and request assistance with research it is vital for National Member Organisations to have good data collection registries to support this need. This is a topic that I will be discussing with the board at our planning day in February and ways to improve our information.

Benefits for patient organisations to twin was also a lecture that offered useful information for IDFA. Twinning is when two neighbouring countries work together on a joint program to support each other and share resources. The lecture used France and Morocco as an example of this.

This conference was an invaluable opportunity to maintain links with IPOPI and other organisations and to ensure IDFA is up to date with latest information and research on a global basis

The idea behind twinning ideally is for a more developed country twin with a less developed country to support the development of countries who have limited resources.

Another topic I found useful was the lecture discussing transitioning from paediatric to adult care. This project is based in the UK. Given my son is approaching the age where he will have to move to adult care, the thought of going from the comfort and supports of paediatric care to the unknown and potentially daunting systems of adult care, is quite a stressful thought for not only myself for many parents who have to go through this process. In the UK they have set up a transitional program to assist the patient, family and medical teams in the process of moving, often to a new hospital or treatment centre and ensuring that information is shared and support is provided to ensure continuity and high quality patient care continues. I thoroughly recommend visiting the IPOPI site and reading the presentation on this topic.

IPOPI board members also talked about the concept of having World Immunology Day each year as a way that all National Member Organisations can globally raise awareness of immune deficiencies and the unmet need for resources, research and funding. I discussed futures planning regarding this topic with the IDFA board at our planning days in February.

The conference offered the opportunity to listen to and discuss many and varied topics and as I cannot discuss adequately, in detail, these topics I strongly recommend spending a few minutes viewing the links on the IPOPI website. All of the lectures and beneficial websites to visit can be found on the IPOPI website:

http://www.ipopi.org/events/istanbul-2010-presentations.html

This conference was an invaluable opportunity to maintain links with IPOPI and other organisations and to ensure IDFA is up to date with latest information and research on a global basis. I would like to take this opportunity to thank the IDFA board, Cathryn and my family for supporting me to attend this conference. As a board member and as a parent of a child with a PID, I found this opportunity invaluable as I learnt so much and having the opportunity to hear others perspectives also challenged some of my own thoughts and values for which I'm very appreciative for the experience.

Tracy Brew
Vice Chair
IDFA

Next IPOPI Conference – Florence Italy 3-6 October 2012

IDFA and IPOPI is delighted to announce the launch of the First World Primary Immunodeficiency Week 2011 (WPIW).

This inaugural week will be celebrated from 22-29 April culminating in the World Day of Immunology on 29 April. In support of the week a dedicated Website has been created **www.worldpiweek.org**

Why not let family, friends and work colleagues know about this new event - send the link by text or email!

IDFA Immune Deficiencies Foundation Australia

The IDFA is a not for profi t organisation dedicated to supporting Australians of all ages diagnosed with Primary Immune Deficiencies (PID's). IDFA provides education for PID's, PID lobbying and advocacy services, and ongoing medical and scientific research.

Web www.idfaustralia.org Freephone 1800 100 198 Fax 1800 100 714 Email info@idfaustralia.org Post PO Box 149 Stroud NSW 2425

IDFA Immune Deficiencies Foundation Australia

InTouch

APRIL 2011

Establishing international awareness and support for PID patients across the Asia Pacific Region

IDFA Board Update

Hello all and welcome to the IDFA newsletter. In my last newsletter article I gave you an overview of the 2010-13 IDFA strategic plan. In this newsletter, I would like to give you an update on the IDFA Annual General Meeting, and on the Board's priorities for the organisation in 2011.

The IDFA Annual General Meeting for 2010 was held on 25 November. During 2010 IDFA recorded a small deficit of $30,000 for the 2009-10 financial year, mainly due to expenses associated with the large patient event we held at SeaWorld. However, IDFA still has cash reserves of around $170,000, so continues to be financially viable. At the AGM, the current officer bearers of the Board were also reappointed:

- Adam Friederich – Chair of the Board (second year of a three year term)
- Tracy Brew – Deputy Chair
- Lara Alexander – Chair, Finance and Audit Committee
- Dr Jane Peake – Chair, Medical Advisory Committee
- Trevor Lowe and Dr Karl Bleasel make up our current Board of six members.

While the focus continues to be on improving the financial viability of the organisation, there is also a focus on delivering services to you, the members of the organisation.

The Board of Directors held its annual planning weekend in Melbourne on 26-27 February 2011, where the Board agreed to the following key priorities for 2011:

- Identify new revenue opportunities
  - three or more significant (>$10,000) funding sources
  - five or more minor (<$10,000) funding or in-kind sources
  - maintain existing funding relationships.
- Increase membership by ~25%.
- Conduct patient meetings in at least Adelaide, Brisbane, Melbourne, Perth and Sydney.
- Conduct activities to increase awareness.

While the focus continues to be on improving the financial viability of the organisation, there is also a focus on delivering services to you, the members of the organisation.

You will see that holding patient meetings in major capital cities remains a major priority. IDFA has also engaged a new patient support services officer – who you will read about elsewhere in this newsletter – to help support our members.

Cathryn Baker, our General Manager, will be going on maternity leave in April. I would like to wish her all the best for the upcoming birth. Cathryn will be back on deck in January 2012. IDFA welcomes Karen Phillips as acting General Manager starting in March.

Adam Friederich
Board Chair

GETTING A BETTER DEAL – HEALTH FUNDS AND TRAVEL INSURANCE

Sherri at IDFA is interested in finding out how effectively Private Health Funds and Travel Insurance coverage are meeting your specific medical needs. Our aim is to identify the companies that provide the best services and claims. Once we have this information we may be able to negotiate a more attractive package for our members.

Your assistance in this quest would be greatly appreciated. Please email details about your experiences and level of satisfaction with your current Private Health Fund to Sherri at: support@idfaustralia.org

Save the date

IDF Australia National Patient Conference weekend 24th and 25th March 2012 in Sydney

Register with Sherri for updates email: support@idfaustralia.org

Our people, our stories

IDFA Welcomes our new Support Services Officer

Sherri Mulconry has been employed as our new Support Services officer. Sherri has been working in the Community Service sector for almost 7 years as a qualified counsellor. Previously, she was employed in the private sector as a customer service representative. She brings an enormous amount of experience in working with individuals and families and is skilled at helping others gain a sense of control in their lives. On accepting the position Sherri said that she was very excited to be working for the foundation. She is looking forward to meeting many of you at our events throughout the year and to developing relationships with the Australian health professionals.

Sherri is based in Newcastle and is available to provide you with emotional support by phone and email and to assist you in gaining access to helpful resources. She encourages you to contact her to discuss how she can best assist you and your family. She also welcomes your ideas and topics for upcoming Newsletters.

Sherri can be contacted on:
support@idfaustralia.org

Upcoming Meetings

The team at IDFA are busy planning the upcoming State Meetings and National Conference.

We would love your input into the topics that are presented. What issues are currently relevant to you and your family? What are the burning questions that you need answered? What information could make your life a little bit easier?

Help us to provide you with the most relevant, innovative and informative presentations for our 2011/12 meetings. Email Sherri at: support@idfaustralia.org

Recent Events Ipopi Conference – Istanbul October 2010

In October last year I was privileged to represent IDFA at the annual Ipopi conference that was held in Istanbul. The conference offered the opportunity to meet Drs, nurses, scientists, patient group representatives, patients and families of people with PIDs from all over the world. I also had the opportunity to attend a number of lectures and discussions regarding topics including current treatments and therapies in different countries, latest research from around the world. Below is a list of some of the lectures I attended and found to be very insightful, thought provoking and interesting. These topics included but were not limited to:

- discussions about topics including world day of immunology,
- transitioning from paediatric to adult care,
- risks of vaccination for PID patients,
- importance of data collection for patient organisations,
- safety and supply of IG products,
- neonatal screening for SCID and other Tcell deficiencies that's occurring in California,
- gene therapy – a possible treatment of the future and developing countries and PID treatments.

I personally found Dr Andrew Cant's lecture about vaccination for PID patients very interesting and thought provoking. Dr Andrew Cant talked about his views on this topic.

Dr Cant believes that it is worthwhile giving vaccines to PID patients, in particular, CVID patients providing that you only give vaccines that are **not** "live vaccines". Dr Cant talked about the fact that giving vaccines such as the flu vaccine are not harmful and in fact may offer some protection from certain illnesses.

To read more about this topic I would strongly recommend going to the IPOPI website and follow the links to his talk as detailed below. I will also point out that other Immunologists present differed in their opinion and listening to their debate with Dr Cant was very thought provoking and may be worthwhile discussing this topic with your own doctor/specialists.

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Medical Matters

Coping with Chronic Pain

When people are diagnosed with Chronic Pain they can experience a wide array of emotions. There is often a sense of grief and loss for their independence and the freedom to carry out their normal activities. It is natural to go into a state of denial for a period of time and feelings of anger and sadness may follow. By reaching an acceptance of their diagnosis, patients are better placed to create a pain management plan that best suits their condition and lifestyle. While there is no cure for chronic pain there are strategies and positive steps to help manage and reduce the effects of pain.

Acceptance

Any type of resistance in life causes more anxiety and negative emotions. Once you accept your condition you can work with it rather than against it. Allow yourself to acknowledge and feel the emotions you are experiencing. It's important to work through any negative feelings rather than try to suppress them as our emotions have a direct affect on our physical well being.

Train yourself to let go of automatic negative thoughts. One way of doing this is to say the word STOP to yourself whenever you catch a negative thought in your mind and replace it immediately with a positive and uplifting affirmation. Focus on the positive things, relationships and activities that you can enjoy.

Support

Access all of the information you can about your physical condition. Ensure you have the right combination of professional resources and treatments as well as emotional support from friends and family.

Have a good working relationship with your doctors and medical health team by keeping them informed of any health changes and not being afraid to ask questions.

Reading motivational, inspiring books and stories about others who have overcome adversity can be a great way to stay emotionally strong and in good spirits. Reading a positive, thought provoking quote each morning can be a good way to start your day.

Balancing Exercise

People with chronic pain often avoid exercise however flexible, toned muscles will generally manage pain better than wasting muscles. Your doctor or health professional can assist you to design a modest, safe exercise program based on your capabilities. It is important to pace yourself appropriately with any physical activity and avoid the "all or nothing" cycle.

Spoil the Senses

It's important to have things to look forward to in life and that's especially true for people who have to endure bouts of pain and fatigue. Create highlights in your day and/or week. Do more of the things you enjoy. Watch your favourite DVDs, listen to uplifting music, read an enjoyable book or sit out in the sunshine. Relax in a bubble bath, create a delicious meal or play with the family pet. Find those things that really make you feel good and do them regularly.

Find your Passion

While it can be hard to focus on anything else when dealing with chronic pain, having an interest or passion that requires your full focus and concentration can be a welcome distraction. What activity, hobby or good cause could you feel excited about?

Could you become interested in a craft, scrapbooking, learning a language, drawing, painting or playing computer games? Have you always wanted to write a book or learn photography? Would you enjoy connecting with friends on Face Book or writing your own blogs? Keep searching until you find something that gets you excited and gives you something positive to look forward to.

Relaxation Techniques

There are many forms of relaxation that allow physical and mental tension to be released from the body. Relaxation helps to reduce tiredness and pain, improves the quality of sleep and increases a sense of personal wellbeing and inner confidence. Relaxation techniques can enable one to cope more effectively with stress.

Types of relaxation include: mindfulness, meditation, yoga, progressive muscle relaxation, guided imagery and visualisations, breathing exercises and colour breathing.

Another therapy that is used to restore a sense of calm is called Emotional Freedom Technique. By 'tapping' with two fingers on the Meridian points on the body negative emotions can be released leaving you to feel relaxed and in control.

I would love to hear your comments and thoughts on this article.

If you would like more information on the relaxation techniques or anything else mentioned please contact me at IDFA

Sherri Mulconry