

THE PITUITARY CONNECTION

NEWSLETTER OF THE AUSTRALIAN PITUITARY FOUNDATION LTD

THE NEWSLETTER OF THE AUSTRALIAN PITUITARY FOUNDATION Ltd

now incorporating the CHILDREN'S GROWTH FOUNDATION Ltd
 PH: 1300 331 807
 Email: support@pituitary.asn.au
 Website: www.pituitary.asn.au
 ABN: 13 088 357 902

MISSION STATEMENT

THE APF'S MISSION IS TO PROVIDE SUPPORT TO THOSE WHO HAVE EXPERIENCED PITUITARY GLAND CONDITIONS. WE PROMOTE AWARENESS AND DISSEMINATE INFORMATION HELPFUL TO THE MEDICAL COMMUNITY, PUBLIC, PITUITARY PATIENTS AND THEIR FAMILIES.

IN THIS ISSUE

Feature Article:	
Adult Growth Hormone Deficiency	1-3
Growth Hormone Therapy for Children	3-4
Patient Stories	
Concerned Parents Want Their Voices Heard	5-6
Adult Growth Hormone PBS subsidy application to PBAC	6-7
What We're Doing - National & State Reports	7-9
APF Matters - Notices and News	9-10
APF State Committee Contacts	11
APF Membership Form	12

This Pituitary Connection Newsletter is produced with the generous support of



FEATURE ARTICLE - ADULT GROWTH HORMONE DEFICIENCY

Dr Paul Lee, Dept of Diabetes and Endocrinology, Princess Alexandra Hospital, Brisbane, Queensland.

It is well-known that growth hormone (GH) stimulates growth in children. However research in the last few decades has shown that GH also plays a critical role in metabolism and in the maintenance of physical fitness and health in adults. GH is the most abundant hormone in the pituitary gland and continues to be produced throughout adult life. The effects of GH are widespread and it plays a general role in maintaining the metabolic process and the integrity of many tissues in the body in adults.

What causes growth hormone deficiency in adults?

The most common cause of GH deficiency in adults is a tumour of the pituitary gland. The tumour may compress the pituitary gland resulting in the damage of cells which produce GH. The treatment of the pituitary tumour itself, either by surgery or by radiation, can also damage these GH-producing cells. Traumatic brain injury such as from a motor vehicle accident is a common but poorly appreciated cause.

What are the symptoms of growth hormone deficiency in adults?

Adults with GH deficiency, whether dating from childhood or acquired in later adult life, develop abnormalities in metabolism and a loss of physical fitness. These patients have a recognizable "clinical syndrome", associated with a characteristic history, symptoms, signs, as summarized in Table 1.

Table 1 - Symptoms and signs of growth hormone deficiency

Symptoms	Signs
Weakness	Increased fat mass
Impaired sense of well-being	Reduced muscle mass
Low mood and motivation	Reduced bone density
Lack of energy and vitality	Thin, dry skin with reduced sweating
Decreased exercise capacity	High blood fats

GH is important in controlling metabolism, especially with regards to how the body uses different nutrient fuels to meet energy requirements. GH stimulates the burning of fat and building of muscle. Adults with GH deficiency therefore develop excessive body fat and a loss in muscle mass. The gain in fat mass increases the levels of blood lipids (cholesterol and triglycerides), increasing the risk of developing diabetes. The reduction in muscle mass also results in an impairment of physical performance and muscle strength.

The combined metabolic and functional abnormalities in adult GH deficiency are accompanied by significant impairment of psychological well-being and reduced quality of life. Patients with GH deficiency experience fatigue, easy exhaustion, and lack of vitality. Recent studies have revealed marked impairment in quality of life regardless of country and cultural background [1].

Thus, the collective evidence indicates that adults who lack GH suffer from metabolic abnormalities, reduced physical fitness, impaired psychological well being and reduced quality of life.

How is growth hormone deficiency diagnosed in adults?

Although the features of GH deficiency are recognizable, they are not particularly distinct and mimic changes of the aging process and a sedentary life. Thus, clinical suspicion of GH deficiency must be confirmed by laboratory diagnosis.

To confirm the diagnosis of GH deficiency in adults, the following are required:

- 1) A GH stimulation test: this is the most reliable test. It is performed in a specialized centre under supervision. Different types of stimulation tests are available, the best known being the insulin-induced hypoglycaemia test.
- 2) Measurement of insulin-like growth factor I (IGF-I): this is a helpful test based on a single blood sample. It is usually low but may be normal in GH deficiency.

IMPORTANT!

A single measurement of GH has no value. Random testing of IGF1 level outside the context of pituitary condition is unlikely to yield meaningful information as its level is affected by many conditions.

WHO TO TREAT?

GH deficiency should be diagnosed by laboratory testing within an appropriate clinical context. Testing for GH deficiency should be considered in patients with a high probability of pituitary disease and manifest clinical features of the syndrome. This includes patients with a history of pituitary disease, radiation to the head, known childhood onset GH deficiency and previous head injury.

Growth Hormone Replacement

The benefits of GH replacement in adults with GH deficiency were first reported in 1989. Since then, the impact of GH replacement has been extensively studied, with long-term experience of up to 10 years indicating sustained benefits.

BENEFITS

GH treatment induces profound effects on protein and fat metabolism. It stimulates the growth of muscle and the burning of fat. Patients who received GH treatment lost fat mass and gained muscle mass. One of the first studies of adult replacement reported a significant reduction of 18% body fat and a corresponding increase of lean body mass of 10% over a 6-month treatment period [2]. These metabolic changes are accompanied by an improvement in cholesterol profile.

The increase in muscle mass during GH treatment is accompanied by an improvement in muscle strength, exercise capacity and performance. Patients on GH treatment have reported improvement in mood, energy, sleep, and vitality. According to the partner, the patients were more alert, active, and industrious, and had greater vitality and endurance during GH treatment [3]. A large survey in 304 patients showed not only an improvement in quality of life, but also significant reduction in the numbers of sick days and doctor visits during 12 months of GH therapy [4].

SAFETY

The experience from several large clinical trials indicates that GH treatment is safe and well tolerated. The most common side effect is tissue swelling caused by the retention of fluid. It is usually mild and resolves in the majority of patients either spontaneously or with reducing the dose of GH.

Conclusions

Based on the global evidence of efficacy and safety, treatment for adults with GH deficiency should be replacement with GH, a principle consistent with the tenet of hormone replacement for hormone deficiency in the practice of endocrinology. This recommendation is endorsed by the Endocrine Society of Australia that adults with GH deficiency should be considered for GH replacement therapy. The Endocrine Society of Australia recommends the therapeutic guidelines of the Growth Hormone Research Society, the US and British Endocrine Societies for the treatment and monitoring of GH deficient patients on GH therapy [5].

References:

- 1) Blum WF, Shavrikova EP, Edwards DJ, et al: Decreased quality of life in adult patients with growth hormone deficiency compared with general populations using the new, validated, self-weighted questionnaire, questions on life satisfaction hypopituitarism module. *J Clin Endocrinol Metab* 88:4158–4167, 2003.
- 2) Bengtsson B-A, Eden S, Lonn L, et al: Treatment of adults with growth hormone (GH) deficiency with recombinant human GH. *J Clin Endocrinol Metab* 76:309–317, 1993.
- 3) Burman P, Broman JE, Hetta J, et al: Quality of life in adults with growth hormone (GH) deficiency: Response to treatment with recombinant GH in a placebo-controlled 21 month trial. *J Clin Endocrinol Metab* 80:3585–3590, 1995.
- 4) Hernberg-Stahl E, Luger A, Abs R, et al: Healthcare consumption decreases in parallel with improvements in quality of life during GH replacement in hypopituitary adults with GH deficiency. *J Clin Endocrinol Metab* 86:5277–5281, 2001.
- 5) Ho KK; 2007 GH Deficiency Consensus Workshop Participants. Consensus guidelines for the diagnosis and treatment of adults with GH deficiency II: a statement of the GH Research Society in association with the European Society for Pediatric Endocrinology, Lawson Wilkins Society, European Society of Endocrinology, Japan Endocrine Society, and Endocrine Society of Australia. *Eur J Endocrinol.* 2007; 157:695-700.

The Endocrine Society of Australia (ESA) holds the view that adults with growth hormone (GH) deficiency are not normal and have impaired health. Such patients have a characteristic clinical syndrome which include abnormal body composition, reduced physical fitness, increased cardiovascular risk factors, osteopaenia and impaired psychological function. Based on evidence that GH replacement is beneficial, the ESA endorses the principle that adults with GH deficiency should be considered for GH replacement therapy. Such patients must be accurately diagnosed. Patients with a history of organic hypothalamic-pituitary disease exhibiting characteristics of the GH deficient syndrome and who fulfil the diagnostic criteria defined by the Growth Hormone Research Society should be considered eligible for treatment. The ESA recommends the therapeutic guidelines of the Growth Hormone Research Society* for the treatment and monitoring of GH deficient patients on GH therapy.

*Consensus guidelines for the diagnosis and treatment of adults with growth hormone deficiency: summary statement of the Growth Hormone Research Society Workshop on Adult Growth Hormone Deficiency. *J Clin Endocrinol Metab* 83:379-381, 1998.

GROWTH HORMONE THERAPY FOR CHILDREN WITH SHORT STATURE AND POOR GROWTH IN AUSTRALIA.

Assoc. Professor Gary M. Leong, Dept of Paediatric Endocrinology and Diabetes, Mater Children's Hospital, South Brisbane, Queensland.

Guidelines for indications for use of growth hormone (GH) therapy in children were recently revised and include some new indications. The aims of GH therapy under the Pharmaceutical Benefit Scheme (PBS) GH program include to promote short-term catch-up growth and final adult height in children with short stature (due to various causes e.g. short-slowly growing children, Turner syndrome, chronic renal failure and GH deficiency). In addition, GH can be used to correct low blood sugar (hypoglycaemia) in newborn babies with GH deficiency. In the recently revised guidelines two new indications include Prader-Willi syndrome and SHOX gene deficiency. For more detailed information about the various indications the reader is referred to the PBS GH Program website where the guidelines can be downloaded (<http://www.health.gov.au/internet/main/publishing.nsf/Content/health-pbs-general-supply-hghapplication>).

While treatment with GH has largely focused on the benefits of treatment with GH on improving final adult height, it is clear that GH has other major effects on the body in children who lack adequate amounts of GH from the pituitary gland. The recent inclusion of the Prader-Willi Syndrome indication for GH until 18 years of age emphasises the importance of the beneficial effects of GH treatment on improving body composition (amount of muscle, bone and fat) during the adolescent transition phase of growth.

There is substantial clinical evidence that in children with severe GH deficiency (e.g. congenital hypopituitarism or acquired childhood GH deficiency) that continued treatment with GH after reaching final adult height has several metabolic, heart and body composition benefits (1,2).

It is generally recommended that in adolescents with GH deficiency who have reached near final adult height after completion of GH therapy, should be reassessed to determine if they have persistence of their GH-deficient state. This may involve re-imaging of the brain and the pituitary gland by MRI and/or re-testing for GH deficiency. Those without a previous defined organic or known cause for their GH deficiency may pass this re-assessment and be defined as having a normal GH state (3).

For those adolescents with a previously defined organic cause for their GH deficiency (e.g. hypopituitarism), it is less likely that this re-testing will be normal. It is in this group of adolescents with persisting GH deficiency who may benefit from GH treatment during the transition adolescent to adulthood phase of somatic growth to decrease the risk of central obesity, diabetes, osteoporosis and abnormal cardiovascular risk factors.

The current PBS GH guidelines, apart for children with Prader-Willi Syndrome, do not allow for treatment of children with GH deficiency beyond the adolescent period after near-final height is attained.

References:

- 1) Clayton PE et al. Consensus Statement on the management of the GH-treated adolescent in the transition to adult care. *Eur J of Endocrinology* 2005;152:165-170
- 2) Leong GM and Johannsson G. Growth hormone deficiency: strategies and indications to continue growth hormone therapy in transition from adolescence to adult life.
- 3) Ho KKY et al Consensus guidelines for the diagnosis and treatment of adults with GH deficiency II. *Eur J of Endocrinology* 2007: 157:695-700.

MEMBERS COMMENTS

While GH deficient -

- I am constantly exhausted & I am sick of not having the energy I require to just be able to do everyday mundane things in life. Family & friends do not understand how much it impacts on your overall wellbeing.
- Lack of energy and motivation, uncontrollable weight gain, low muscle tone, tendon injuries.
- It's hard to describe the biggest impact when it's all linked. I developed osteoporosis when I was 21 (having been off GH for almost 5 years). I broke my leg badly and then two ribs. I have/had the body of a frail old woman at age 21. The lack of energy and constant weight gain. It's a catch 22, how can you exercise if you don't have the energy. The mood swings have affected relationships.
- The biggest aspects of GHD are the increase in tiredness and exhaustion at the end of the day, even causing me to have naps in the afternoon frequently. This is compounded by the increased weight levels which add to the feeling of lethargy.
- Without GH I am listless, always sleepy and short tempered. I suffer anxiety and feel strained at all times. I am always overweight and restless. I have trouble with keeping "on the ball". I lack direction in my attitude. My lack of energy and lack of general wellbeing was the necessary reason for me to retire as an invalid.
- I would like to try GH but the current cost is too much. If I were able to at least trial it to see if it does make a difference, it would give me much relief to know that I have done all I can to improve my health.
- The saying "bone weary" now has complete meaning. There are times that you are so tired you just don't care.
- How do you explain to family and friends why you no longer visit them or why you are not traveling to see them? It has torn our extended family away from us. They don't understand how we can go to a Dr and not 'get well'. My father went to his grave calling me 'lazy'.

When taking replacement –

- Very exciting! I hope this is successful!!! I have lost 5kg in 6 weeks on GH! And was able to attend a party for my mother - I was not scared to chat and did not feel the need to stay away... Everyone there thought I was 'all better' again. I am a self funded retiree aged 50 but would like quality of life too. Already I am planning a part time photography course (my former job) and a return to my hobby of genealogy. Not to mention sorting through 5 years of neglected house work/cupboard sorting etc.
- Taking GH replacement, I look more normal, reduced fat / weight and a huge improvement to overall well being and stamina.
- Increased appetite, blood sugar and maintained body temperature.
- Our son has benefited enormously from taking GH since the age of one. It has enabled him to maintain normal blood sugar levels, develop muscle tone and grow at a steady rate in line with his peers. To withdraw this treatment as he approached adulthood would be detrimental to his health, both physically and mentally. We are concerned that the cessation of GH will affect his physical appearance and health, thus affecting his self-esteem and inevitably his future well being.
- It feels like I have blood in my veins again. I wake up feeling refreshed. I feel 'happy' and motivated to exercise and socialise again. I can feel the weariness leaving me. I feel 'alive'.
- I was not able to work before taking Growth Hormone. I started a job a few months after. I also had to sit down after simple tasks. I could not clean my house, I could not mind my Grandchildren which I do now. I also do errands for my elderly mother and take her shopping, I could not do these things before and it caused a lot of anguish and guilt as I did not know the difference until I started on growth hormone replacement and got my strength back. My husband has a normal wife again who is able to participate in life again. I find it hard to detail my life as there is no quality of life without GH replacement - it is the hormone that was missing.
- As the parents of a growth hormone deficient (adult) daughter my husband and I have been sharing the financial cost since our daughter has had to purchase the growth hormone. It is a large financial burden for us. She had time without it in her teens, but her quality of life was so drastically diminished it was clear that it was absolutely necessary. We have opted for the most that we can afford. It is really very disturbing to us since she has been through so much and is so courageous in dealing with all her health issues. It just seems so harsh to still have this avoidable ongoing strain placed on her.

PATIENT STORY -

CONCERNED PARENTS WANT THEIR VOICES HEARD

David and Narelle, Victoria, Australia



We were aware that our daughter Angela was short in stature when she was about two to three years of age. But we were not tall either so just put it down to 'family genetics'.

It was not until she was 7 years of age that she was diagnosed with growth hormone deficiency (GHD).

GHD is not a common health issue. Conditions like diabetes are more common, and therefore it has an increased awareness in the community. Not so with GHD. To say the least, Angela's story has been quite a journey.

It is hard to remember all the emotions that we felt at that time, or have experienced over the years since that day we were informed of her condition. Like all parents who learn their child has a chronic health problem, we felt isolated, sad, scared and unsure of what lay ahead for her.

Our story really began in 1986 when Angela was 7 years of age. Tests conducted at the Royal Children's Hospital in Melbourne confirmed that Angela's pituitary gland produced very little GH. Angela required an injection of synthetic GH daily, with one day off a week to replace what her own body was not able to produce.

Angela has always been very resilient, and was blessed with a strong personality. These characteristics have helped her 'get through' the tough times. Feeling different to your peers is hard, no matter what age, but particularly when you are a young child or a teenager.

In 1994, Angela discontinued the synthetic GH, because under the Pharmaceutical Benefits Scheme (PBS), the guidelines of the Pharmaceutical Benefits Advisory Committee (PBAC) deemed that Angela had reached 'the adult height threshold' and this was one 'criteria' for ending the subsidised supply of growth hormone. Her adult height was 1.60 metres and was taller than her mum who was 1.58 metres tall. That always was a bit of a family joke.

This was actually an exciting time for her (and us) because she did not have to have any more injections.

As a 15 year old teenager she was all 'grown up'. We thought this was the end of her 'health story' and the start of a new journey. How naive we were.

Over the next few years Angela experienced a number of related health issues. These issues included mood swings, weight gain, lacking energy, and the eventual diagnosis of osteoporosis, whilst she was studying at university in Canberra. A consequence of this was a serious fracture of her leg while playing sport (a normal activity for a young adult). This event raised our awareness of the apparent need for growth hormone in adults to enable them to enjoy good health.

Subsequently, at age 21, from 2000 to 2002 she participated in an adult 'Growth Hormone Trial' at St Vincent's Hospital in Sydney conducted by Professor Kenneth Ho (endocrinologist), where she was given synthetic GH. During the period of the trial, Angela enjoyed the health of a young adult, experiencing weight loss and a feeling of well being.

At the completion of the trial she again stopped taking growth hormone, because supply of GH for adults was not provided for under the Guidelines for the Availability of Human Growth Hormone (hGH) as a Pharmaceutical Benefit (the Guidelines).

Angela decided that for her to continue to live a healthy life, she would have to purchase synthetic GH at a cost of approximately \$1,000 per month. Naturally this cost "to be well", impacted on her ability to live even a relatively modest lifestyle.

In early 2009 Angela travelled to the UK to reside and work professionally. Once there, and under the care of the endocrinology team at St Bartholomew's Hospital in London, Angela undertook the required tests to become eligible for the subsidised supply of synthetic GH and was accepted into their health scheme. Angela's UK endocrinologist at that time prescribed a higher dose of GH as it was decided that the lower GH dosage prescribed in Australia was not adequate for best health outcomes. The financially significant outcome of the UK Health Service prescribed treatment was that Angela's personal commitment for her ongoing good health was reduced to approximately \$15 (Aus) per month for her synthetic GH.

Current information indicates that adults with GHD are more likely to develop conditions such as osteoporosis. Other health issues such as weight gain, depression and elevated cholesterol levels could increase the risk of these adults developing cardiovascular disease long term.

Such costly conditions contribute to over 30% of Australia's total burden of death, disease and disability according to the latest figures released by the Australian Government.

New Zealand has recently approved the subsidised use of GH replacement therapy for adults deficient in GH through Pharmac (our version of the PBS). Australia is therefore now the only western country where adults with growth hormone deficiency do not have access to affordable synthetic human GH.

In 2007-08, only 2% of the total health expenditure in Australia was designated for preventive services or health promotion.

If more funds were invested at the grass roots level, through early intervention and health promotion, it is obvious that the subsidised cost of medications through the PBS such as 'synthetic growth hormone' would be far cheaper for Australians compared to the cost required to manage the complications of conditions such as cardiovascular disease and osteoporosis in the medium to long term.

It does not make sense, and doesn't seem right, that another country is able to offer our daughter a necessary drug for her health and well being at an affordable price, and our own country (the so called lucky country) has resisted making available synthetic GH available to dependant adults at an affordable price.

Angela is now 31years of age and continues to enjoy excellent health in all aspects thanks to the synthetic GH. She must soon return to Australia as her working visa has expired. She has, however, been invited to continue to work for her organisation in London and they have agreed to sponsor her visa application. Naturally Angela would love to remain in London to enjoy the health benefits available to her there.

How do we feel now at this point of Angela's journey? We know Angela will continue to be well while she is making such appropriate health choices and we are so proud of her and of all her achievements in life.

We are however very frustrated and are totally unable to understand the short sighted approach of the Australian Government/s who continue not to effectively address this ongoing health crisis. Being healthy is the right of all Australians. It is time the Australian Government/s recognised and addressed this issue.

Angela is a long way from us and we miss her terribly, but to us, her health and happiness are paramount. It is sensible that she live where her health is appropriately supported.

Sadly, Australia does not provide a pro active and supportive health system for adults with GHD.

IT'S TIME! LET'S GET MOVING ON SUPPORTING THIS APPLICATION!!!

In 2001 an application was made, and rejected, for GH to be placed on the PBS for adults and adolescents with pituitary disorders. Pfizer Australia has decided to apply in 2011. The APF is deeply involved in supporting the application, and we encourage our members to do the same.

The benefits and contradictions of Growth Hormone replacement therapy for adults within Australia have not been well studied compared to overseas countries such as UK and USA.

There are no estimates available in Australia, however estimated prevalence in the UK of 0.02% (Reference: Society for Endocrinology. Topical briefings: adult growth hormone replacement. Bristol, UK: Society for Endocrinology; 2001) and based on the projected number of adults (18+) in 2011 (17,308,709) there are approximately 3,461 patients with growth hormone deficiency as adults in Australia.

Here in Australia, the government currently funds growth hormone replacement for children with a diagnosed deficiency and a small number of other disorders characterized by poor growth. As of May 2010 there are 1636 children receiving GH treatment in Australia under the PBS. Most children on the scheme will be deemed "adults" under the current criteria at the age of 14 years.

The application for listing Growth Hormone on the PBS other than for growth in childhood in 2001 failed. Since then approval has been granted to Prader-Willi children up to the age of 18. This indicates that the government has recognised the metabolic advantages to receiving GH. Adding your voice to others calling for the PBS approval of GH for adults will help bring about change.

Want to be involved?

If you, a member of your family, or someone you care for suffers from a deficiency of growth hormone, there are a number of things you can do to help us:

1. Write your story...

Now is the time! March & April is best.

Write a letter directly to PBAC. Template letters are available on our website to assist you to do this. The APF recommends contacting your treating health professionals – GP, Endocrinologist, Physician etc. and ask them to supply you with a supporting letter, stating the benefits you may experience by taking GH replacement, or indeed any proven benefits if you are already receiving GH, focusing on the impacts on your quality of life. Attach this to your letter.

Encourage your treating health professionals to write personally in support of the application to PBAC.

Fax or post a letter to the PBAC directly, enclosing a letter of support from your treating health professionals.

Write to your local Member of Parliament about your personal experience with growth hormone deficiency and ask for their support in getting AGH replacement onto the PBS.

Go to our website www.pituitary.asn.au and look for the Growth Hormone Advocacy page. There you will find draft letters to assist you. Each letter has a different focus, including information and awareness for Ministers and MP's. The letters are drafted in the positive, ie: the benefits. As the application is assessing the benefits of growth hormone approval for adults, a "benefits" approach is recommended.

A website link to all federal members in Australia is also supplied there.

2. Complete our short survey... go to www.pituitary.asn.au

For the purposes of the survey participant's responses will be de-identified.

Your responses will assist the Foundation in preparing a comprehensive quality of life submission on behalf of all Australian adults and adolescents seeking to have Growth Hormone as an affordable option in the future. Some APF questions are quite personal, and the survey allows you to submit without your name and contact details if you so wish.

3. Submit your information online... 25 May 2011 to 8 June 2011

Most importantly you will have a short window of opportunity to submit responses to five key questions direct to the PBAC website in 2011. Direct submissions can only be registered from 25 May 2011 to 8 June 2011. These responses will be reviewed by the PBAC prior to the meeting in July. Pfizer will be providing the PBAC with detailed clinical and economic data, so your responses to the PBAC's questions should highlight the QUALITY OF LIFE issues for people affected by growth hormone deficiency.

Each question will take a maximum of 200 words. If you would like to learn more about PBAC meeting and consumer input please go to the Dept of Health & Ageing

website. More information is also available on www.pituitary.asn.au

We must be heard.

Managing a pituitary condition is challenging enough. It can predispose us to other medical problems such as diabetes, osteoporosis, depression and fatigue. Australian pituitary patients with growth hormone deficiency who cannot afford access to this essential replacement hormone may indeed progress to other / additional serious medical conditions or diseases - haven't we been through enough? Prevention is better than cure. Let's prove to the Australian Government, through our voices, the benefits of receiving "complete" hormonal replacement.

WHAT WE'RE DOING – National & State Reports

A message from the Chairperson

Happy New Year to all fellow Australians. The commencement of 2011 has been fraught with problems for some. I sincerely hope that those affected by the natural disasters are beginning to get on their feet once again. It's times like these you have to be mindful of having a good supply of medication at home or with you at all times.

This year is proving to be a busy year. We are happy to report that we have secured funding to proceed with the planning of educational seminars in 2011, and our committee and state coordinators are busy with this task as I speak. Thank you to our sponsors. Novartis, Pfizer, Merck Serono, SciGen, Ipsen, Novo Nordisk, Ferring for their contributions towards education. Ipsen for sponsoring our newsletter and Pfizer for sponsoring the maintenance and improvement of our website.

Application by Pfizer (the sponsor) to the Pharmaceutical Benefits Advisory Council for Genotropin to be listed for subsidy for use by adults who are growth hormone deficient is very exciting news for many. A contributing factor to the failure of a similar application in 2001, based on the information supplied, was uncertain clinical benefit, particularly the lack of evidence to suggest an improvement in "quality of life" and the resulting uncertain cost effectiveness. To this end we are hoping that all members, families and health professionals will submit their personal testimonials.

Again I thank the state coordinators for the wonderful work they do.

Noel Hickey

SA

Saturday 2nd April

Want to enjoy a film night? We've booked the Wallis Theaterette at Richmond to see two movies - Four Holidays and Gran Torino! A comedy and a very good drama together. These nights are always fun and we keep the cost low to encourage people to attend. So, round up your families and friends – the theaterette seats 60 and we hope to fill those seats! I will give a brief overview on what has been happening in the APF and advise about upcoming seminars. I hope to see you at the film night.

- Saturday, 2nd April
- Come at 4.30pm - Films start at 5pm
- Bring a plate or basket of food to share
- Coffee, tea etc provided. BYO cold drinks.
- RSVP – 28th March to Loretta on 08 8293 4566 or sa@pituitary.asn.au

Paediatric Support

We hope to have Animal Capers to do a presentation for children in the near future. A date is being chosen and invites will go out soon.

Loretta

WA

Presently we are in need of a volunteer to join with us in coordinating support in Western Australia.

It could be you or a family member, such as your partner or parent. Whilst the national committee will remain active in providing email and telephone support and coordinating major events in WA, such as seminars, we need a member who loves helping people by arranging the occasional meeting. Please call us to discuss.

TAS

We thank Melissa Syme from Tasmania for her work as state coordinator for the past couple of years. Unfortunately due to work restraints Melissa has stepped back. Is there anyone in Tasmania who would like to enjoy volunteering for the Foundation? Tasmania has a very small membership however we hope to see that improve.

NSW

Adult Support - Saturday 5th March

One of our members is very excited about doing a fundraising and social event for APF! Rochelle has Acromegaly and she preferred to call the event "Acromegaly High Tea" as she is presently managing Acromegaly - but of course anyone can attend.

Please, can I encourage you to be there with your families, friends or loved ones? It is being held in the Hunter/Newcastle region – if you do not live in this area, perhaps put the day aside for a nice drive and lots of fun. A big thank you to Rochelle!

- Saturday 5th March, 1.30pm - \$5 entry includes Tea/coffee, cakes etc. and lucky door prize
- Salvation Army Hall, 156 Bay Rd, Bolton Point 2283
- Auctions, trade table of handmade items
- Tax deductible donations gratefully accepted
- All monies to The Australian Pituitary Foundation
- Bookings essential (for catering and seating)
- RSVP - 1st March to Rochelle on 0416423912 or rochellebuckley@optusnet.com.au



Paediatric Support - Saturday 2nd April

We will be holding a family fun morning with Taronga Park Zoo Mobile visiting us with various reptiles, frogs etc for the kids to enjoy. The plan is to enjoy the 1hr presentation then lay back for a sausage sizzle in the park.

Bring the family, siblings are welcome. The venue, Putney Park, is a very popular park located next to the Parramatta River. It is a great place for family picnics with beautiful waterviews in the background. The Park has electric barbeques, and a big shelter we can use.

- Saturday 2nd April, 10.00am - includes children handling the reptiles at 10.30 – 11.30am and a sausage sizzle BBQ at 12noon.
- Putney Park, Pellisier Road, Putney. Putney is in the northern suburbs and is approx. 16km west of Sydney CBD. For more information go to <http://familyfunsydney.blogspot.com/2009/11/putney-park-putney.html>
- BYO cold drinks
- BYO deck chairs and sunscreen
- RSVP – 28th March to Daniel on 02 9792 1340 or nsw@pituitary.asn.au

QLD

Seminar News - Saturday 21st May

I'm delighted to report that an educational morning will be held at Princess Alexandra Hospital on Saturday, 21st May. Currently the program is being put together. When this is complete we will release it to those on our database. Please check our website regularly where you will be able to download the flyer. Thank you must go to speakers Dr. Ross Cuneo, Dr. Paul Lee, Professor Ken Ho, Dr. Sarah Olson and PA Hospital Endocrine nurses..

Adult Support

Saturday 19th March Anna Petrou from Synapse (formally known as Brain Injury Association of Qld) will speak on what Synapse does, and then cover some details about the brain and how it works. Often depression and living with a disability can affect someone's behaviour. Anna works alongside Synapse Community Response Service and Client services. Join us for afternoon tea.

- Saturday, 19th March, 2.00pm. 2.30 – 3.00pm for presentation, 5pm close
- BYO a plate for afternoon tea
- RSVP – 16th March to Sue on 07 3376 2083 or qld@pituitary.asn.au
- Venue (Brisbane) details supplied on RSVP

Paediatric Support - Sunday 20th March

Geckoes Wildlife Presentations fun day for families. Bring the siblings and enjoy a sausage sizzle BBQ. Venue is a private residence at Mt. Ommaney in Brisbane.



All families with children affected by pituitary disorders are welcome – just call us to let us know you are coming!

- Sunday, 20th March, 10.30am -11.00am start for presentation, 12noon sausage sizzle BBQ
- BYO cold drinks
- BYO sunscreen (we will be under a covered area)
- RSVP – 16th March to Sue on 07 3376 2083 or qld@pituitary.asn.au
- Venue (Brisbane) details supplied on RSVP

APF would like to thank Geckoes Wildlife Presentations for partially subsidising this event. I have seen their presentations and have no hesitation in recommending them. Ph: 07 3289 4709 or visit their website www.geckoeswildlife.com.au

Sue

VIC

Another new year has begun and already Christmas feels like a distant memory. We celebrated the occasion here in Victoria with a lovely dinner in Williamstown at a great venue overlooking the ocean, where we also enjoyed some very informative discussion. It was really great to see a few new faces, both new members and paediatric attendees.



Dr. Margaret Zacharin (left) from the Royal Children's Hospital gave us all an insight into the pituitary problems encountered by the younger members of our community and Zoe Nicholson (right) imparted a wealth of knowledge about nutrition and healthy eating.

I think everybody was surprised by the demonstration of portion sizes. I think they were equally surprised (and more than a little pleased) to be told that chocolate and wine were perfectly ok to be included into a healthy diet. Which was lucky as most of the Christmas Choccie boxes were empty at the end of the evening!



All in all we had about 40 guests who, once again, appreciated the opportunity to share their experiences, catch up with and make new friendships. We will definitely do it again at the end of 2011! In the meantime, plans are underway for another series of educational and support gatherings for our state. Dates have yet to be finalised but I will endeavour to have it all put together over the coming weeks, however, I need your help!! We have covered a number of topics over the past couple of years that have been of great interest and value, but is there

something that you would really like to see or hear about? We understand that there are many issues that affect us as pituitary patients, the physical also spilling over into emotional and relationship concerns. I do not wish to revisit the same material over and over again so...Is there a particular topic that you feel would be helpful? Please, email me, phone or write and let me know (as soon as you can) so that I can try to provide some new knowledge that will benefit you.

Kellie

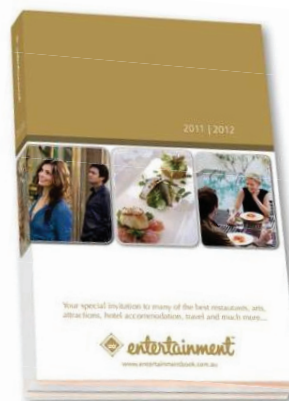
APF MATTERS – News & Notices

Help us to raise vital funds

The new 2011/2012 Entertainment Books are coming soon!!

Your special invitation to save at many of the best restaurants, arts, attractions, hotel accommodation, travel and much more.....With over \$15,000 in offers, The Entertainment Book is a must have for any household. Books are available for cities across Australia starting from early April. Get in early and pre order your Entertainment Book before March 31st and you will receive Bonus offers for NEW businesses in the Book valued at over \$100 that you can use now through till June 1st.

Enclosed with this newsletter is the order form – please ask family, friends, neighbours and work colleagues if they would support us by ordering as well! Or you can download an order form from our website www.pituitary.asn.au



Bonus offers are limited and are issued on a first come first served basis.

Book Prices are as follows;
Sydney, North Sydney, Adelaide, Brisbane, Melbourne and Perth are \$65.00

Sydney Greater West and Newcastle \$60.00

Canberra, Geelong, Gold Coast and Tasmania are \$55.00

Enquiries to
NSW Daniel Blomfield..... nsw@pituitary.asn.au
QLD Tania Halford..... mio_rossa@hotmail.com
VIC Kellie Dines..... vic@pituitary.asn.au
SA..... Loretta Schar sa@pituitary.asn.au

DVD's of previous educational seminars are now available

Finally after much preparation, copies of some previous educational seminars are now available on DVD for members. Order forms to members are also included with this newsletter - this is strictly a pre-order arrangement – once numbers are finalised we will know how many to reproduce. Remember to send it back within the closing date.

New Understanding Your Pituitary Problems Book (second edition) and Diagnostic Literature

So much work has gone into developing these books. Thanks must go to Jennifer Gan and Paula Donaldson, medical writers, Kathryn Skelsey (APF member) who is preparing the illustrations, APF members who have contributed photos and quotes to personalise the book, Professor Steven Boyages, Professor Ken Ho, Dr. Robert Smee, Dr. Paul Lee and Lynne Schofield, endocrine nurse, who contributed to the completion of the book.

It is anticipated the book will be ready to release to all members when they renew their membership for 2011/2012 year. Renewal notices will be going out towards the end of May.

Acromegaly Support Group New Zealand

Acromegaly Support Group was launched in November 2010, with the aim to provide information and support to New Zealanders with Acromegaly.

The group produces regular quarterly newsletters, organises social gatherings and educational seminars. As well as providing a way for sufferers and their families to communicate and share their experiences. Email: pituitarynz@gmail.com. Phone: 021-293 5506. Visit their website: www.pituitary.org.nz

Dr. Catherine Chan, a medical doctor currently working as a GP registrar in Auckland set up the group. Catherine has acromegaly which was diagnosed in 2004.

New Zealand lacks an association/society for pituitary patients, the formation of this support group is wonderful news for people with Acromegaly.

Australian Pituitary Foundation welcomes people with pituitary disorders from New Zealand to become members and share our networking resources – such as a patient contact register and secure chat forum. We aspire to have New Zealand as a Chapter of the Foundation, however we need the membership to build and a dedicated person to become the coordinator. If you have an interest in helping us in this way please contact us.

We look forward to communicating more with the Acromegaly Support Group New Zealand and congratulate Catherine. It is hoped she can visit us this year at one of our seminars.

Can you put half an hour aside to write a story?

Please, would you consider writing your personal story? It is good for APF to have a balanced variety of stories, and of late few have been coming through. A photo would be nice, we always find it adds that personal touch, however if you wish to be anonymous we can arrange that as well. Email membership@pituitary.asn.au PLEASE!

Member's Only Chat Forum

Participation has slowed down. We wonder if it is because there is no set time allocated for communication. Please email membership@pituitary.asn.au if you think a set time for sessions would be beneficial. Eg. every second Monday evening between 7pm -8pm.

THINGS WE'RE UP TO

ESA/SRB will be held in Perth this year in conjunction with APEG conferences. The Foundation plans to attend and will have a booth to display our work and resources to health professionals who work in the field of endocrinology.

Our AGM is gearing up to be exciting with Kellie organising the day on Saturday 17th September.

The venue will be in Geelong and Kellie is presently making enquiries to hold a personal development workshop (or similar) for members while taking a short break to do the formalities of the AGM. At this stage we imagine it will be a lunch time affair with the workshop in the afternoon, so please, keep the date free. Mid day has been selected to give people an opportunity to drive to Geelong.

The Foundation would not run without the support of its members. A current director would like to retire, and we are searching for some-one who has a passion to get involved. It is always good to have change, with new people coming on board to offer different ideas to take the Foundation forward.

The committee communicates usually via. email and teleconferences, but we take the opportunity for a face to face planning day or weekend at least once or twice a year. Would you or a family member be interested in knowing more? Please contact us.

Become an APF Member
Membership Form on last page or
Download a membership form from
www.pituitary.asn.au

PITUITARY AWARENESS

Linking People With Information



AUSTRALIAN PITUITARY FOUNDATION

Newsletter Publishing and Mailouts

If you wish to receive the newsletter by email, which will help us considerably with mailing costs, send an email to support@pituitary.asn.au

DTP & Printing: Tannah Graphics Pty Ltd, Brisbane.
The Pituitary Connection © Australian Pituitary Foundation Ltd.

Next Newsletter

If you would like to contribute, please send your submission by email to membership@pituitary.asn.au or fax it to 07 3376 2896. Photos and graphics are always very welcome.

The next edition is planned for May 2011
Deadline: 30th April, 2011.

Disclaimer

The information in this Newsletter, whether provided by APF or any third party, is not intended to be used as a substitute for professional health or other advice. You should not rely on this information to make decisions about your health or lifestyle without consulting a health professional. APF does not accept liability for any injury, loss or damage incurred by use of or reliance on information in this Newsletter.

Privacy Policy

AUDITOR: AAT Accountants Pty Ltd, PO Box 270, Albany Creek. Qld 4035 Ph: 07 3264 4180

APF COMMITTEE CONTACTS

NATIONAL

Address: PO Box 105, Kellyville NSW 2155

Phone: 1300 331 807

APF Email: support@pituitary.asn.au

Chairperson – Noel Hickey

Secretary – Eric Kozij

Email: support@pituitary.asn.au

Treasurer – Sue Kozij

PO Box 570, Mt. Ommaney, Qld 4074

Ph: 1300 331 807

Email: treasurer@pituitary.asn.au

NEW SOUTH WALES

Daniel Blomfield

Ph: 02 9792 1340

Email: nsw@pituitary.asn.au

ACT

Juliet Langridge

Ph: 02 6244 3794

Email: act@pituitary.asn.au

QUEENSLAND

Sue Kozij

Ph: 07 3376 2083

Email: qld@pituitary.asn.au

SOUTH AUSTRALIA & NT

Loretta Schar

Ph: 08 8293 4566

Email: sa@pituitary.asn.au

Pam Nicholson

Ph: 08 8243 0957

Email: nicholson48@optusnet.com.au

Sylvia Robb

Ph: 08 8384 3690

Email: probb@chariot.net.au

VICTORIA

Kellie Dines

Ph: 03 5259 2809

Email: vic@pituitary.asn.au

WESTERN AUSTRALIA

C/- Ph: 1300 331 807

Email: wa@pituitary.asn.au

TASMANIA

C/- Ph: 1300 331 807

Email: tas@pituitary.asn.au



MEMBERSHIP FORM

New Membership
 Renewal

Membership of the APF will benefit yourself and also help us to support other patients and families with our newsletter and services. All information on this form is confidential and voluntary and complies with our Privacy Policy which can be viewed at www.pituitary.asn.au. The information below will allow us to conduct statistical surveys and provide services to you.

APPLICANT'S NAME:

Mr/Mrs/Ms/Dr/Prof _____

PATIENT'S NAME:

Mr/Mrs/Ms/Dr/Prof _____

POSTAL ADDRESS: (Including title, company / hospital if applicable).

CITY _____ STATE _____ POSTCODE _____

PHONE: (H) _____ (W) _____

MOBILE: _____

EMAIL: _____

ALTERNATE EMAIL: _____

Is the applicant a (please tick)

- Patient
- Family Member / Friend / Carer? Please specify (eg. mother?) _____
- Health Professional: Please specify (GP, Endocrinologist) _____
- Other: _____

Date of Birth (Patient): / /

Gender (Patient): Male / Female

WHAT PITUITARY CONDITION were you ORIGINALLY diagnosed with?

(ie. The main cause of your current pituitary condition) Please select only one.

What condition(s) do you have NOW (since treatment)?

Please select more than one if required.

Original	Now	Original	Now
<input type="checkbox"/>	<input type="checkbox"/> Acromegaly	<input type="checkbox"/>	<input type="checkbox"/> Hypopituitarism (some hormones)
<input type="checkbox"/>	<input type="checkbox"/> Adult Growth Hormone Deficiency	<input type="checkbox"/>	<input type="checkbox"/> Late Effects - Cancer Treatment
<input type="checkbox"/>	<input type="checkbox"/> Auto Immune	<input type="checkbox"/>	<input type="checkbox"/> MEN - Type1
<input type="checkbox"/>	<input type="checkbox"/> Brain Injury	<input type="checkbox"/>	<input type="checkbox"/> Panhypopituitarism (all hormones)
<input type="checkbox"/>	<input type="checkbox"/> Brain Tumour	<input type="checkbox"/>	<input type="checkbox"/> Pit. Adenoma - Unknown Type
<input type="checkbox"/>	<input type="checkbox"/> Childhood Growth Hormone Deficiency	<input type="checkbox"/>	<input type="checkbox"/> Pit. Tumour - Non-functioning
<input type="checkbox"/>	<input type="checkbox"/> Congenital (at birth)	<input type="checkbox"/>	<input type="checkbox"/> Pit. Tumour - Multi Hormonal
<input type="checkbox"/>	<input type="checkbox"/> Craniopharyngioma	<input type="checkbox"/>	<input type="checkbox"/> Prolactinoma
<input type="checkbox"/>	<input type="checkbox"/> Cushing's Disease	<input type="checkbox"/>	<input type="checkbox"/> Rathke's Cleft Cyst
<input type="checkbox"/>	<input type="checkbox"/> Diabetes Insipidus	<input type="checkbox"/>	<input type="checkbox"/> Septo-Optic Dysplasia
<input type="checkbox"/>	<input type="checkbox"/> Haemorrhage	<input type="checkbox"/>	<input type="checkbox"/> Sheehan's Syndrome
<input type="checkbox"/>	<input type="checkbox"/> Head Trauma		
<input type="checkbox"/>	<input type="checkbox"/> Other: _____		

Comments on Pituitary Conditions _____

Taking GH? Y N GH Pay? Y N GH Trial? Y N

Are you willing to assist with advocacy to get Growth Hormone listed on the PBS? Y

Treatment: (Please tick box, circle where required)

Also specify type / dates / doctor/ hospital / number of times if you wish)

Surgery? _____

Radiotherapy? _____

Pituitary Medication Names _____

Medication comments _____

Vision Problems? Y Microadenoma? Y Macroadenoma? Y

Pregnancy Tried post diagnosis/treatment? Y Success? Y N

Are you in Remission Y N Time to diagnose _____ years

APF SERVICES:

I would like to receive the newsletter by:

Email Mail Both (please assist us by selecting email)

I would like to receive: Brochures No. _____

Posters to display in my professional rooms or wards.

Some members have expressed the desire to be able to contact fellow members. The Phone and Email Patient Contact Register is designed to enable contact between patient or family / carer members with their permission. You might like to be part of this Register. If so, please tick your preference where indicated below.

Please include my name and contact details on such a list: my phone my email both

I would like to be added to the APF members email group. <http://health.groups.yahoo.com/group/apfmembersgroup/>

I am interested in helping the APF with: _____

I heard about the APF from: _____

I am a patient / carer / health professional (please circle) and am willing to talk with the media Y

All memberships are **\$35.00 - 1 year** or **\$90 - 3 years** and are renewed at the end of the financial year - **30th June**. Applications received after 31 March are entitled to membership until June of the following year. Please forward this completed application form with your payment to:- **The Treasurer, Australian Pituitary Foundation Ltd., PO Box 570 Mt. Ommaney Qld 4074**. If you have selected to pay by credit card you can now fax this form to (07) 3376 2896. Please consider a small donation to cover merchant fees.

Alternatively you can now join on line and pay via [pal upon our website. www.pituitary.asn.au](http://www.pituitary.asn.au)
Donations of \$2 or more are tax deductible, so please consider making a donation! Your contribution will be gratefully accepted!

Membership: \$35/1 year \$90/3 years

Donation: \$ _____

TOTAL: \$ _____

- Cheque/money order enclosed payable to Australian Pituitary Found. Ltd
- Visa / Mastercard (please select)
We cannot accept other cards.

Cardholder's Name _____

Card Number _____

Expiry Date _____ / _____ / _____

Signature _____

I do require a receipt.

PLEASE NOTE: A receipt will not be sent unless requested in the tick box above.

IMPORTANT: Please sign and date the form.

I consent to the collection and storage by the APF, of personal and health information which I have supplied above. Please view our Privacy Policy at www.pituitary.asn.au (Please tick the box, and sign below.)

Signature: _____

Date: _____

If you have questions or require assistance regarding membership please contact Sue.
Email: membership@pituitary.asn.au
Phone: (07) 3376 2083