



THE PITUITARY CONNECTION

NEWSLETTER OF THE AUSTRALIAN PITUITARY FOUNDATION LTD

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MISSION STATEMENT

The APF's mission is to support and educate people impacted by pituitary conditions. We convey awareness and provide relevant information to the general and medical communities and act as a collective voice for pituitary patients and their families.

IN THIS ISSUE

Advocacy Notice and Patient Testimonials and Stories	1 - 3
What We're Doing – National & State Reports	3 - 6
APF Matters - Notices and News	6 - 7
Removal of blood glucose test strips from the Pharmaceutical Benefits Scheme on 1 July 2016	6
Fundraising	7
APF State Committee Contacts	8

NOTICE:

Currently there are 2 new medications being submitted to the PBAC for subsidy.

- 1) Growth Hormone for severely deficient adults
<http://pituitary.asn.au/Advocacy/CurrentGrowthHormonePBACSubmission.aspx>
- 2) Pegvisomant – an additional therapy used for people with excess Growth Hormone where other therapies have not responded well
<http://pituitary.asn.au/Advocacy/CurrentMedicationforAcromegalyPBACSubmission.aspx>

The consumer window is NOW OPEN for submissions and testimonials. More on Page 4 of this newsletter.

Patient testimonials and stories:

Too little Growth Hormone:

I was treated with GH as a child under the government's subsidised scheme and treatment was ceased as a 17yo. Once treatment stopped, GH deficiency severely affected my studies and employment. I was constantly fatigued, exhausted & was overweight. I had reduced muscle mass with a lot of abdominal fat, and felt that I couldn't exercise or function as a 'normal' person. I became a homebody; preferring to stay away from every function. If I did venture out, I would become so tired that I would even fall asleep at traffic lights, whilst the car was stationary. When I wasn't working, I was lying about at home with no energy to do anything; not even basic household chores or grocery shopping. Some family and friends do not know about my pituitary disease, and I am embarrassed to tell them about my GH deficiency because they would probably feel more comfortable thinking I was 'lazy'. To some people, I've always been the 'lazy one', the 'quiet one', the 'chubby one', the 'homebody' and when I was not being treated with GH, I

didn't even have the energy to offer an explanation.

GH deficiency is a disability and you do feel isolated at times and it seems that nobody understands your daily struggle. That, in turn, makes you depressed and anxious about the past, present and future. When I recommenced GH treatment as a 36yo, it changed my life completely. I am able to successfully function as a mother, wife, friend, and worker. My general health and blood tests improved, my weight normalised, the abdominal fat disappeared and I could exercise again. Mentally and socially, I am present in everybody's life and can contribute so much more on a daily basis. I sleep better, I am able to concentrate on the tasks at hand and I am motivated to get out and about with my family and friends. Paying for the GH treatment myself is a financial burden on my family, but everybody has seen what a huge difference it has made to my life. I'm working to pay for the GH, but the reality is that if I didn't have the GH treatment, I don't think I would be able to work or function effectively!

Accessing Growth Hormone is required for my son to partake in all aspects of his life. The financial burden of buying this necessary drug, which cannot be duplicated by any other method, has required my working each evening following my day of high school teaching, working Saturday and Sunday morning, and a significant increase in a credit card debt. I am driving a sixteen year old car and am now looking to sell my house. We cannot save, we do not have family support, we must move from our house and all this increases his anxiety which is not beneficial to his well-being.

The financial toll is extraordinary for a single income parent. Yet without this drug every aspect of my son's life is affected. His sleep, energy levels, and general well-being require growth hormone. Having attended a selective academic school he was unable to complete the HSC. Next, when attempting a bridging course to University, he was required to take a leave of absence due to ill health. He will now be eighteen months behind his peers. Socialising required huge efforts and as his health is quite varied, he is

losing social connections. Given this scenario, what mother would not do all that is available, to aid his health and opportunities to study. Given the success of the removal of his craniopharyngioma, it is an enormous pity that continuing to improve my son's health comes at the price of all other aspects of family life being affected. He was also a great sportsman being in the top ten of three sports at representative level. Without Growth Hormone he cannot participate at any level. This has caused him great distress. This drug is a requirement and ultimately it will cost my family our home. The case is obvious, as a parent I can attempt to provide the best medical options to give my son the opportunity to live a fulfilling life but the cost is significant and deprives the family of any other choices. My son's life has been significantly compromised, socially, sporting, academically and he bears an enormous weight, adding to the serious anxiety that comes from a serious medical condition. He now feels that he has placed the family in a very precarious position and that makes recovery all the more difficult.

I'm not taking growth hormone at the moment, I would if I could afford it - and I am scared I'm going to die young and alone. I can't relate to other people my age and sometimes I feel so tired I just want my life to end. I'm just so tired.... I am very ambitious but I feel like I lack in being able to do the grunt work and having the energy that everyone else has. I also feel like my head is foggy and everyone else can see clearly.

When I was on growth hormone, I studied part time, worked full time and was able to do normal things on the weekends. Now it disgusts me that I'm so tired I've had to put Uni on defer and all I do is watch TV. That's not a life worth living. I want to own my own business, do wonderful things - be proud of myself. The simple return on investment by investing in people with GHD is massive - the extra amount of money we can generate for the country is a no brainer. I'm sick of letting this illness define me. I am ANGRY about other countries like NZ and UK not forgetting people like me - but because of my illness I have no fight left in me. I've given up. I just want to enjoy my life.

Too much Growth Hormone:



Pete: As a young man I was fit and well, played sport (Aussie Rules, Rugby and American Football). In 1999 I married the love of my life, and had two children – the first child in 2001 and the second in 2003 - both boys.

Life was good, but back in 2005 I noticed that things were changing. My wedding ring was not fitting anymore, I had headaches, aches and pains and generally overwhelmed with fatigue. I was seeing a dermatologist for skin cancer and he noticed the size of my feet and asked if I had ever been tested for acromegaly. I was, like, “what is that” .??

I had blood tests and was sent to an endocrinologist who sent me for an MRI. I was then advised I had a tumour the size of a large grape on my pituitary gland. The first thing I thought was “who was going to look after my wife and kids”. My endo doctor then told me it was benign, though I was still thinking the worst and was relieved to know I wasn't going to die just yet.

I started on injectable medications which I did not tolerate well, but the meds did shrink the tumour. I missed a bit of work through sickness but lucky I had a good boss. I went through regular appointments at the hospital and regular jabs in the bum (I won't lie - they hurt like hell). This went on for a few years.

In August 2008 I had my tumour removed surgically but they were not able to remove the whole thing as it was wrapped around the main artery in my neck. I was taken off my medication for a short while but my IGF-1 was still up over 900 and my GH levels were still high, about 30 when it should be below 10. After my surgery I was very weak and I was unable to do much, but over time I was starting to feel better. The headaches were going, some of the symptoms were going, the puffiness in my hands were going down. I was still having MRIs to check the tumour all the while going to work at a local Council doing manual labour driving trucks, tractors and all kinds of small machinery.

In June of 2009 I started a six week course of radiation therapy, so every day I was driving to Sir Charles Gardiner Hospital laying down whilst they were zapping what was left of my tumour. I was told by my doctor it would take at least 5 to 6 years for any residual tumour to die and I was still having blood tests. My IGF-1 levels were not going down nor were my GH levels.

So a couple of years later my doctor sat me down and told me of a drug he would like to try but it was expensive. There were only 4 other people in Australia who were taking it and my doctor really wanted me to take it because he had talked to other endocrine doctors who had said that it was the best way to go as my IGF-1 and GH levels had still not come down. The hospital agreed to subsidize the injection but only on a six month trial and I'm glad they did! I had a blood test and after about a month from commencing I saw my doctor again who advised me that my IGF-1 and GH levels had started to come down. I was overjoyed that this was finally happening and so was he. I was on the medication for about 18 months all up and had never felt better.

I was thankful to my doctor and the hospital for giving me the chance to try Pegvisomant as it has changed my life for the better. My IGF-1 levels are still high but my GH levels are now normal thanks to this drug. I'm now no longer on any drugs but still have regular blood tests and checkups and although I still have acromegaly I do not have to endure the debilitating symptoms and the tumour has gone.

Too much Growth Hormone:



Stephanie - 23: As a teenager I was very fit and active. I attended a performing arts high school and was dancing 6 days a week. After high school I moved out of home and attended University in Bathurst, studying education. I was having the time of my life, not a care in the world.

In my second year of Uni I began having chronic headaches, where my left eye would swell and begin watering. I didn't really notice it at the time, but I had also gained weight and my shoes didn't seem to fit me anymore. I tried to self-diagnose my headaches, by having my eyes checked and even having my wisdom teeth removed. But the headaches continued and were getting worse and my left eye was constantly swollen. In August 2012 I went to the doctor because I hadn't had a period in almost a year. My doctor sent me for a blood test, which had very abnormal results, and then for an MRI, which showed a mass in my pituitary gland that was pressing on my optic chiasm and wrapped around the left carotid

artery. I was numb when I heard the news. "I'm only 19. This isn't fair. Why me!"

I had surgery late 2012, but they were unable to remove the entire tumour because of how close it was to the optic nerve and carotid artery. After surgery I was constantly tired and still had headaches. My Growth Hormone was still very high (over 400 when it should be below 10!), as was my IGF-1. I began injectable medication, which helped with the fatigue; however, I was travelling back to Sydney every month for this injection.

Mid 2013, my Growth Hormone levels had risen dramatically, 998! Plus the tumour had grown back and was now bigger than when I was first diagnosed. Radiation was the next option. In October 2013, I moved back to Sydney to begin a 7-week course of radiation. My mum and I would drive to Prince of Wales Hospital every day so I could lie down for 20 minutes and have my head zapped. I struggled with the radiation. I had almost no energy, lost a scary amount of weight and was in so much pain that I was put on heavy painkillers.

Because it was going to take some years for the residual tumour to die, and my Growth Hormone was showing no sign of coming down, my endocrinologist recommended a different injectable medication, Pasireotide. Only a handful of people in Australia were on the medication, but it had promising results. After 18 months on Pasireotide my GH levels had dropped below 100! I was astounded. I had more energy and less headaches. Unfortunately, it was around this time that I was diagnosed with medically induced diabetes, a common side effect of the medication, and began taking insulin needles.

I have now been on Pasireotide for two and a half years and my latest GH results are 20.9. I am astonished with how effective this medication is and how much it has transformed my life. I was able to finish University and begin full time work as an early childhood educator with the help of this drug. The tumour continues to slowly shrink and I have my diabetes under control. I am so thankful to have to the team of doctors I have and the love and support of my family and friends. I may still have acromegaly, but I am finally starting to feel more normal.

WHAT WE'RE DOING – NATIONAL & STATE REPORTS

A Message from the Chairperson

Well! It's been excitement all round in the pituitary community! Notices have been "flying out the door" to members, doctors and other interested parties:

It is exciting news that Pasireotide was released under subsidy for use on 1st September for those where current therapies available in Australia have not been successful for people with ongoing acromegaly. Whilst this is a highly regulated drug it is wonderful news for those who are continually fighting disease progression. <http://pituitary.asn.au/NewsandEvents/CurrentNews.aspx>

Two additional applications for subsidy on important medications are currently being considered by the PBAC and the Foundation intends to have a very strong consumer voice. Please see the info further along in this newsletter.

Our AGM, this year, is planned for the evening of 25th October. A notice will be sent out to the members in order for you to register your participation via. teleconference. The APF is currently undergoing a period of positive transition and as part of this it is looking to restructure its Board and will be looking to fill up to 5 vacancies on the Board, due to a number of Directors retiring and the need to bring new skills. To continue the important work of the Australian Pituitary Foundation, we need a strong Board to set the strategic agenda and continue to build effective partnerships and align to our Mission Statement. Part of this transition also is to adapt a new constitution which we have been working on with our lawyers over previous months.

Malini

The consumer comment window is now open!!!

We would like you to help us with both consumer activities.

1) **Growth Hormone** is an integral part of standard replacement therapy for patients with established pituitary disease; its benefits have been well studied and its guidelines for use published by various Endocrine Societies worldwide. Sadly, currently in Australia, Growth Hormone is not subsidised for use by severely deficient adults. The focus this time is on improved quality of life, which of course is a consequence of better general health or adequate management of disease.

Many concerned parents and adults have been contacting the Foundation regarding the lack of subsidy for growth hormone for deficient adults. It is very concerning, financially, emotionally, physically, mentally...

APF is aware of some adults who require Growth Hormone but "do without" because of the financial cost. Some adults find the funds through hard times, or take out a loan. Parents of children who are no longer eligible to receive Growth Hormone through subsidy, feel isolated and "responsible" that they cannot afford this daily medication to assist the cellular and brain development of their adolescent.

So, round 3 here we go!!! The window is now open for consumer comment. Get your consumer comment in as soon as you can, and encourage your family, friends, supporters and health providers to also submit. If Australia is successful in acquiring subsidy, it gives people with hypopituitarism hope for their future health and well-being...

Please also help us by completing this survey
www.surveymonkey.com/r/ZRXB3K7

2) Calling all patients who have or have had acromegaly. As only a handful of people have been prescribed **Pegvisomant** in Australia it is difficult for Australian patients to have a strong consumer voice on the therapy. Where we can help, is by informing the government about Acromegaly and the effects this disease has on people's lives. We encourage you, your families and friends who know you, supportive work colleagues and health care providers to write in to support this submission to add an additional subsidised proven therapy for people with aggressive Acromegaly in Australia.

APF also invites you to participate in our survey which will help us complete an organisation submission.
<https://www.surveymonkey.com/r/YBTM7LQ>

You may have been treated for Acromegaly and now find you have hypopituitarism and are now deficient in growth hormone. You may be coping without this essential hormone or paying for it. This is the time to lend your voice to also support the application for Growth Hormone subsidy... And, support APF by completing our survey to help with an organisation submission.
www.surveymonkey.com/r/ZRXB3K7

IF YOU HAVE BEEN A RECIPIENT OR PRESCRIBING DOCTOR OF PEGVISOMANT CAN YOU PLEASE MAKE CONTACT WITH APF AT support@pituitary.asn.au

Seminar News:

Our inaugural paediatric education day in Queensland was thoroughly enjoyed by participants as far away as Warwick, Bundaberg and even a grandparent who flew in from Adelaide.

Thanks must go to many people, in particular Nurse, Jennifer la Cour and her team for putting the program together and making the day such a wonderful event.

Content covered all things paediatric - The Pituitary Gland "101"; Septo-Optic Dysplasia: Puberty, Precocious and Delayed; Craniopharyngioma; Schooling and Camps; Emergency Plans and Sick Day Management Injection Workshop, concluding with an informal interview of a family and mature aged son on their perspective of treatment and support; and an endocrinologists take on managing a child with panhypopituitarism.



Families lining up for the Solu-cortef injection workshop with Karen Bragg and Jen la Cour



Dr. Yassmin Musthaffa, Nurse: Jen la Cour, A/Prof Louise Conwell, Prof Jerry Wales



Kim Bennett & Mary Collis, State Schools Nursing Service



Dr Dianne Jensen and Dr Robert Campbell



Dr Andrew Cotterill with Connor and his parents.



Mums and Grandma's networking during the morning.



Two little friends meeting up again on the day...

Thanks to my wonderful daughter Jen, who always volunteers to help me out at these sessions.

Sue

NSW

Social News:

Dr Ann McCormack hosted an education morning for adults at the Garvan Institute of Medical Research in May. There was quite an audience there and it was also an opportunity for some of our new Directors and Board advisors to attend to gain a better understanding of the challenges faced by pituitary patients.



Kimberley Au with Sue Kozij from APF.



A/Prof Clare Fraser, Beth Killen from APF with her specialist, Dr Mark McLean.



Dr Ann McCormack & Dr Cecelia Gzell.

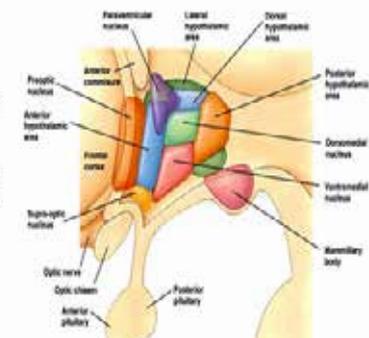


A lot of research to prepare for the 50+ years of the pituitary at St. Vincent's Hospital. APF.

Hypothalamic nuclei

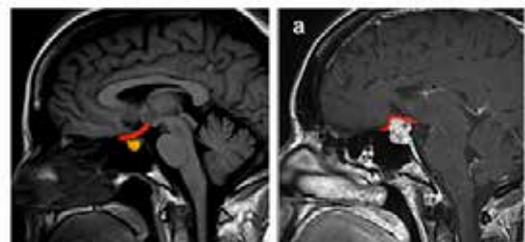
Nuclei of the Hypothalamus

- Hypothalamus is made up of numerous small nuclear masses called hypothalamic nucleus.
- Many functions beyond hormone control
 - temperature
 - appetite
 - fluid balance
 - sleep/wake cycle



The Hypothalamus regulates the cyclic activities of the body on a 24 hour cycle

Pituitary tumors and vision





That evening, a dinner was enjoyed by a number of people including patients, partners, doctors and stakeholders.

Daniel

ACT

Social News:

We had a great catch up early July when Sue & Eric Kozij visited Canberra. The weather was "freezing" and we all met in the warmth of a Service Club for dinner. Was great to have a couple of "paediatric" families join us. Sue & Sophie were particularly happy to see one another as it has been years since their last meeting which was in Brisbane. It is hoped I can develop the ACT membership and encourage people to join us.



Celia

VIC

Seminar News:

I am planning a get together somewhere around Federation Square late October and Invites will be available soon.

Steve

WA

Social News:

As you know already I will be retiring as WA state co-ordinator at the end of the year.

Very soon I will be sending out invites so we can all get together before then. I have truly loved the work I have done for the Foundation, but it is time for me to concentrate on my health and family. This does not mean that I will not be attending our socials in the future and will continue to see you all.

Pete

APF MATTERS - NOTICES AND NEWS

Removal of blood glucose test strips from the Pharmaceutical Benefits Scheme on 1 July 2016

From 1 July 2016 blood glucose test strips were no longer be available on the Pharmaceutical Benefits Scheme. They can still be accessed through the National Diabetes Services Scheme (NDSS). People registered with the NDSS may continue purchasing blood glucose test strips as a subsidised product through the scheme. A series of frequently asked questions regarding access to blood glucose test strips and other changes to the NDSS is available on the Department of Health website.

Please email the Diabetes Products Section at ndss.products@health.gov.au for more information.

New Fact Sheet Design:

Thanks Marleen, what a great job you are doing in developing our new fact sheets into something that we can be very proud of. Keep an eye out on the website as they will be uploaded soon.

Website:

We've had a bit of a catastrophe where our website developers decided to close their doors without any notice! Unfortunately due to their lack of response to previous requests we are now endeavouring to recruit a new developer and rectify many issues with the website. If you are having trouble logging in to renew your financial membership, please contact us on membership@pituitary.asn.au

Videos of Educational Days:

APF has been so fortunate that the majority of our presenting doctors have agreed to have their presentations recorded for educational purposes. We are in the process of post-production at the moment and will have them uploaded to the member section of our website soon. If there is a member who would like to help with this please call Sue on 1300 331 807.



Fundraising:

Thanks Lisa for all you and Jack did in the City to Surf Run in Sydney in August! Lisa earned a wonderful \$1,254.00 by supporters. Doesn't little Jack look awesome in his pituitary awareness tee-shirt. Lisa tells us Jack conquered Heartbreak Hill like a true champion and he wasn't giving up.. Jack had a much needed nap after the 2km of Heartache but finished walking across the line eating a banana. He is very keen for next year!!!! Not too late to donate..

<https://city2surf2016.everydayhero.com/au/lisa>



Kara's Mum sadly Mum lost her fight to the effects of Cushing's Disease around 15 months ago. She contacted APF a while back asking if she could help to raise awareness of the disease whilst also raising funds for the Foundation. So, here she is about to run her first ever marathon - the Melbourne Marathon.

<https://give.everydayhero.com/au/melbourne-marathon-run-for-mum-to-help-find-a-cure-for-cushi>

"Thanks to all my supporters to date and a special thank you to my Dad.

Maybe you too could run in the Marathon and we could meet up and have a great time! Think about it....

The more people that know about Australian Pituitary Foundation, the greater their impact, so please spread the word by sharing my page with your friends and family. Thank you in advance for your generosity, it means a lot!"

My brother is also running in memory of my Mum (his Aunt) please visit his page here

<https://give.everydayhero.com/au/help-me-find-a-cure-for-cushings-disease>



Yi Yuen Wang is a Neurosurgeon with a strong interest in achieving excellence in pituitary outcomes. He is committed to pursuing excellence in pituitary care. Yi Yeun has allocated the funds from his run to Australian Pituitary Foundation to assist us meet our mission to raise awareness of pituitary disorders and provide support to patients and their families.

1 in 20 people will have a pituitary tumour and the time from symptoms to diagnosis can be as long as 10 years. Early recognition of pituitary disorders will allow prompt treatment and maintenance of a normal hormonal environment. This is particularly important in children with pituitary hormone deficiencies when early intervention may allow normal growth and development to occur.

<https://give.everydayhero.com/au/yi-yuen-s-marathon-effort>

APF COMMITTEE CONTACTS

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Next Newsletter - If you would like to contribute, please send your submission by email (membership@pituitary.asn.au) or fax it to 07 3376 2896. Photos and graphics are always very welcome. The next edition is planned for November 2016 **Deadline: 15 November 2016**

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. The content of patients stories are the opinion of individuals and not the Australia Pituitary Foundation or its office bearers. 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:** to see our Privacy Policy go to www.pituitary.asn.au **AUDITOR:** Paul D Teefy PO Box 288, Ashmore. Qld 4215 Ph: 07 5503 0088



Australian Pituitary Foundation

Tax Deductible Donation Appeal

Thank you for your tax deductible donation to the Foundation. Your contribution is sincerely appreciated and will assist the Foundation to meet its mission to support and educate people impacted by pituitary conditions. We convey awareness and provide relevant information to the general and medical communities and act as a collective voice for pituitary patients and their families. You can securely pay on line using the donate button at www.pituitary.asn.au

YOUR NAME:

YOUR COMPANY/ORGANISATION (if applicable)
.....

ABN:

POSTAL ADDRESS:

STATE: POSTCODE: PHONE: EMAIL:

Any Special Notes ?

Can we include you on our database to be informed of future events or information? Yes No

Method of Payment: Cash Cheque Credit Card Tax Deductible Donation: \$.....

Visa Mastercard _____ / _____ / _____ / _____

Unfortunately we cannot accept other cards.

Cardholder's name: Cardholder's signature:

Expiry date:/..... CVV:

Please return this form to: Australian Pituitary Foundation Ltd, PO Box 570, Mt. Ommaney. Qld 4074
Fax: 07 3376 2083, or scan to treasurer@pituitary.asn.au