Acromegaly patients lost to follow up…..
could this be you?

Ann Robinson Nurse Practitioner
President Endocrine Nurses Society Australasia

A research group in Brazil reviewed the medical records of patients with acromegaly to determine if any had been lost to follow up. They also wanted to find the reasons why patients were no longer attending the clinic to access treatment and if there were any differences between the group lost to follow up and those still continuing with routine specialist acromegaly treatment (Kasuki et al., 2013).

239 files from 3 centers in Brazil were reviewed. The files consisted of all the records for acromegaly patients diagnosed between 1994 and 2009. Patients who had not been reviewed in over 12 months were contacted and invited to join the study. 42 patients were considered lost to follow up this criteria and an attempt was made to contact this group.

The records at the last visit before lost to follow up were reviewed and the last recorded blood test results were assessed to determine disease control at that time. Medical treatment was interpreted as those being treated with the somatostatin receptor analogue Sandostatin LAR, cabergoline or a combination of both treatments.

The IGF-1 (indicator of acromegaly control) at the last visit was found to be

• Normal at the last visit in 8 of the 42 patients without requiring medical treatment
• Normal in 6 patients receiving medical treatment
• Uncontrolled (above the normal reference range) in 28 patients (66.7%)

17 patients agreed to be in the study. 15 of these had active acromegaly during the evaluation period. All 17 agreed to restart treatment. The reasons given by the patients for not coming back for future treatment and follow up included

• “I thought I was cured”
• “I do not feel sick”
• “I moved to another city”
• “I am being treated at another hospital”
• “I do not have time to attend my appointments”
• “I do not have money to come to the hospital”

In the discussion the article describes how acromegaly treatment has changed over the past few decades and that treatment options are increasing. Despite this, the cure rate for macroadenoma with extrasellar extension, generally remains at less than 50%. Continuing therapy with medications remains necessary for many patients. Acromegaly is a chronic disease that requires adherence to therapy plus modifications to that therapy from time to time. The long term risks from uncontrolled IGF-1 and growth hormone include heart failure, sleep apnea, hypertension and increased mortality. In this study active patient follow up allowed the restarting of treatment in 40.5% of patients lost to follow up.
The authors encourage centres managing acromegaly patients to actively search and reconnect with patients lost to follow up to allow resumption of treatment where necessary.

Following the pilot study in Brazil a French group conducted the ACROSPECT study (Delemer et al., 2014). The objective being to gain an estimate of patients lost to follow up and to find out the impact this had on the disease and its management. Patients from 25 centres in France were traced and identified as lost to follow up if they had not had an entry in their hospital records during the previous 2 years. In this study the files of 2392 patients were reviewed and 512 (21%) were considered lost to follow up. The reason most commonly cited for abandoning follow up was not being informed of the need for long term follow up. Patients had also moved away or had difficulty travelling to the specialist center.

The research team was able to contact 300 patients and 87 agreed to be in the study. They were interested to find out if the decision to abandon specialist care was detrimental to patients. They commented that patients often lose motivation due to the demands of being managed in specialist centres where the care complies

with the guidelines but can be a long way from home and with limited collaboration with local doctors. Analysis of the findings suggested that patients no longer attending specialist follow up were not receiving optimal care. The study concluded that more work needs to be done to inform patients of the need for long term follow up as the absence of this will be detrimental to their health.

While no study such as those in Brazil and France has been conducted in Australia there are possibly patients here that have been lost to specialist care and may be unaware of the long term consequence of elevated IGF-1 and growth hormone levels to health. If this may be you or someone you know it might be time to reconnect with your specialist endocrinology team again.


For people with acromegaly: There are 2 injection services available which may assist by alleviating the stress of travel, parking, navigating the hospital, waiting times etc. associated with appointments.

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<th>ASSIST</th>
<th>SHINE</th>
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<td>Assist is a nurse program for patients that have already been prescribed Somatuline Autogel and meet the approved TGA indications. This program is an in-home (or convenient location) injection service for patients on Somatuline, or can provide training for patients who are eligible and willing to self-inject, as well as ongoing support. All ASSIST nurses are trained to answer patient queries about the ASSIST program and to provide support during their visits.</td>
<td>The SHINE home injection service has been developed to support patients who have been prescribed Sandostatin® LAR® (long acting release octreotide) and whose condition is stable.</td>
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<td>Patients are encouraged to contact the ASSIST Nurse Coordinator on the toll-free number 1800 277 774 throughout their treatment if they have any questions about the ASSIST program. The ASSIST Nurse Coordinator is a registered nurse who is available to answer calls during business hours, Monday to Friday (9 am to 5 pm Australian Eastern Standard Time).</td>
<td>The program includes access to a SHINE nurse who will administer Sandostatin® LAR® according to clinician directions at the patient’s home, place of work, or at the location of their choice (even while travelling within Australia). Wherever possible the same SHINE nurse visits the patient each time, developing a supportive and trusting relationship.</td>
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<td>Patients are reminded that the ASSIST program complements but does not replace usual specialist care.</td>
<td>The SHINE nurses provide ongoing information and support including monthly updates to clinicians about their patient’s progress. Patients continue to attend clinic visits for review with their treating doctor every 3 – 6 months depending on their health status. Patients on the SHINE program can discuss any queries by contacting (02) 9439 9770.</td>
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If you have or have had Acromegaly or Cushing’s Disease and are not regular with your appointments, we’d love you to complete a survey developed in conjunction with the Endocrine Nurses Society of Australasia. https://www.surveymonkey.com/s/FTD6987
A Message from the Chairperson

Our AGM was conducted on Sunday, 18th October and since then we’ve partaken in big changes.

We have commenced restructuring the Board to bring on more skilled directors and consolidate our strategy.

Historically our Board has been comprised by mainly patient members, who, while passionate about the organisation and creating awareness for pituitary conditions, lacked the corporate and technical skills, qualifications and networks to drive the organisation further.

As a result, we have recently recruited 4 new directors, Peter Welburn, Sarah Clarry, Malini Raj and Melissa Muratore. Collectively, they have a solid foundation of experience in areas of Finance, Accounting, Governance, Human Resources, Health Care and Pharmaceutical Experience, Marketing, Communications and relevant networks etc. With this, we are now in a position to take the APF to the next level. We also welcomed Beth Killeen as a Director and she has taken the role of Secretary. More directors will step down in the near future as we recruit additional suitable Directors. We will formally introduce your new Directors in the next newsletter.

We are particularly looking for volunteers with professional skills in marketing, fundraising and endocrine health who can share their industry skills. People with personal connections to pituitary would be ideal, (even family or close associates) however this is not a fixed prerequisite.

There are so many people to thank who have worked tirelessly on the Board of the Foundation, some for many years.

In particular those who have recently retired: Noel Hickey, Russell Fairweather, Daniel Blomfield, Simon White & Cristel Woelfel. Don’t worry though, you will see them at local functions and they remain devout volunteers for the Foundation.

Additionally APF would like to thank our sponsors. Without financial support from Novartis, Ipsen, Novo Nordisk, SciGen, Pfizer and Ferring the Foundation would not have been able to achieve the highly successful projects completed in 2015.

On behalf of us all I wish you and your families a wonderful festive season and a bright wonderful New Year full of happiness and good health.

Sue

QLD

Social News:

Had a great day with the usual crowd in November. As heat waves were overwhelming us on the eastern side of Australia we decided to give the ferry ride up the Brisbane River a miss and instead have a BBQ at our place with the air conditioner going full ball! Some stayed back for a swim in the pool.

Then the following Saturday a few of us gathered at Masters to do a sausage sizzle fund-raiser. We had the banner up and had conversations with a few people regarding the pituitary gland and the endocrine system in general. So, killed 2 birds with one stone so to speak – fund-raising and awareness all in one hit.

Thanks so much to the people who assist me here at the Queensland branch, we always have such fun and it was lovely to see you all.

Sue
NSW

Social News:

First of all I would like to say Merry Christmas and a safe New Year and I am looking forward to seeing you in 2016.

Our latest get together was at a little café in The Rocks it was nice to see some old and new faces and finally getting to meet our newest board member Malini Raj. These little get togethers are laid back and every one can talk about these conditions and just chit chat over some lunch. I was asked if it is possible to have more regular get togethers, and in the New Year, with the help of some volunteers, I will organize small café meetings on a regular basis in Sydney every month or two.

I decided to step down as a board member and just concentrate on NSW. I would like to thank all of the old board and the new board for the time that I have spent helping the Foundation.

Daniel

VIC

Social News:

We had a great little Xmas party a few weeks ago at the ACMI café/bar in Fed Square with around a dozen Victorian members catching up and some of us meeting for the first time over a nice dinner and a few drinks or two!

It was a great little venue, easy for everyone to find & get to, and besides from the good old Melbourne weather being predictably unpredictable and forcing us all to sit inside, it was a really good opportunity for all of us with previous and ongoing pituitary conditions to catch up, network and compare a few experiences and stories. With the Xmas party on the same weekend as the GPCE at the exhibition centre at Southbank we also had a few interstate visitors with Malini Raj, our new Non-executive Director and Treasurer and Director Sue Kozij down from Sydney and Brisbane to run the Pituitary Foundations stand at the GPCE. Melissa Muratore, also a new Non-executive Director came along with her son, Gabriel, who everyone adored. All had a good old time and we wish everyone a Merry Christmas and Happy New Year and good luck with any New Year’s resolutions!!!

Steve

WA

Social News:

Hi all, it’s nearly Christmas and another year is almost gone. We had a get together at the Dome Café in Hillary’s and had a fair turnout on a rainy day, but it was enjoyed by all. We even delighted in an unexpected (and free!) performance from a group of synchronized swimmers in the water right near our table!

From all of us here in Western Australia I hope you all have a great Christmas and a safe and happy New Year.

Pete
Steve Lewis:
The Directors would like to introduce Steven Lewis who will take care of the members in VIC. Steve has undergone two surgeries for a macro-adenoma and is keen about contributing to making a difference to the lives of those living with pituitary disorders. Steve is also keen to increase the membership base in Victoria and encourage younger persons to become involved.

GPCE:
The Brisbane GPCE concluded recently. We were fortunate to have Dr Viral Chikani, Staff Specialist at Princess Alexandra Hospital, present for us on all three days.

The APF’s workshop, “Could it Be the Pituitary - The Master Gland?” was well attended by delegates. It highlighted current scientific research for the prevention, treatment and cure of pituitary disorders. It also provided a forum for questions and discussion of problems related to the alleviation and care of pituitary disorders.

Doctors and nurses who attended the conference accessed up to date information about APF’s support network. Our display was a hive of activity at different times of the day as delegates took advantage of the opportunity to ask questions and get information. Many were pleased to learn more about the APF’s purpose built resources portal for GPs and health care providers.

Many thanks to the Pituitary Foundation for facilitating attendance at the recent GPCE in Brisbane for myself and Drs Natalie Old and Manju Luchmaya.

The weekend was a great opportunity for us to update and upskill in a number of areas. Your stand was informative and the pituitary workshop was very well presented.

As GPs, we all each have patients who have suffered from pituitary conditions. As you are well aware, they can present with subtle and often confusing signs and symptoms. Continuing to remind us about their importance will help with early detection and treatment. Keep up the good work!

Warm regards, (Dr) Robyn Shirlaw.
What an amazing gesture on the part of the Australian Pituitary Foundation (APF) to offer complementary registration to the General Practitioner and Practice Nurse Clinical Education (GPCE & PNCE) Conference held in Brisbane, 11 -13 September. My attendance would not have been possible without the APF’s support.

The presence of APF at the conference highlighted its vital role as not only a community resource on tap to pituitary patients and family members but also to the public and health care professionals.

Overall, the GPCE & PNCE conference presented an excellent opportunity to update knowledge as well as network with colleagues from different disciplines. The conference venue was easily accessible and the overall program was well organised. The diverse displays and presentations were very informative.

Dr Toni Dowd, Registered Nurse / Community Advocate

Thanks to our sponsors which funded our attendance at this event

The exhibitions varied in Brisbane with some new stalls – one of which was the Cancer Council QLD which Sue Kozij visited. Did you know that Cancer Council Qld has an excellent Brain Tumour Support Service. Don’t be misled by the word “cancer” and think you cannot be included. The Service provides for those with benign tumours and recognises how dangerous they can be if not managed well or treated successfully. Anne-Marie and Sue go way back, with Anne-Marie being instrumental as a support person while Sue was being diagnosed around 19 years ago!

If you or someone close to you has been diagnosed with a benign or malignant brain tumour, coping with changes to your life can be stressful and challenging. Cancer Council Queensland’s Brain Tumour Support Service provides resources, information sessions with health professionals, and opportunities to meet others dealing with a brain tumour. Our 13 11 20 staff can also assist with referrals to Cancer Council Queensland support programs and other community services.

To access this service or sign up to the quarterly e-newsletter phone 13 11 20 or email btss@cancerqld.org.au.


Regarding the other state Cancer Councils:

All other Cancer Councils can provide support and information. Services are varied across the states and phone 131120 in your state to ascertain what support or services can be provided.

WA Practice Nurses Association (WAPNA)

At the recent GPCE in Perth, a Practice Nurse won our “Passport Voucher”. Pete had extensive discussions with her and subsequently APF was invited to speak at one of their meetings.

Pete Marsh presented his story on receiving a diagnosis of Acromegaly, the impact on him and his family, work, and subsequent treatments – one of which was a trial on Somavert (Pegvisomant) which is currently not available for use in Australia. Pete, now, incredibly is in remission from Acromegaly due to the trial.

Lana Kelly contributed a moving story on her car accident, subsequent decline in health, and eventual diagnosis of panhypopituitarism. She endured a “closed head” injury where the MRI shows the gland had been knocked off the pituitary stalk. Lana prefers not to call the incident an “accident” as she was hit by a drunk driver.

The nurses, Pete and Lana really enjoyed the evening and APF received a small monetary gift of appreciation from the Association.

The Western Australian Practice Nurses Association was established to provide a forum for Western Australian nurses, who are employed in general practices, doctors' surgeries and clinics, offering them opportunities to meet, update their medical knowledge and nursing skills, and interact socially.

Presentations are given by guest speakers at the monthly educational meetings and two professional development educational programs are offered annually.
Last Newsletter: X-linked Acro-gigantism Syndrome - Story of Claire.

APF would like to thank young Claire so much for allowing us to share her story through our newsletter.

Readers will be pleased to know that Claire is keeping very well and is currently overseas having her first post-surgery review. Ironically Claire is now growth hormone deficient, and due to her height may not be eligible for subsidised growth hormone to help her with her development. Her mum and dad are ardent supporters to assist with an advocacy drive towards a future growth hormone submission. Want to be involved too? Call us.

Please see a video documentary Claire’s family produced to share her unique story:-
Part 1: https://www.youtube.com/watch?v=lv1Lx0hgMjk
Part 2: http://www.youtube.com/watch?v=PEwu2OOrXG0&sns=em

MANAGEMENT OF ACROMEGALY

AIMS OF TREATMENT

Therapy is directed towards:

• Making the GH oversecretion return to a normal level and
• Reducing local complications from the mass effects of the pituitary tumour without disturbance of other pituitary functions

There are currently three ways of treating acromegaly:

• Surgery
• Radiotherapy
• Medication

Frequently, two or more of the treatment options may be necessary to treat acromegaly effectively.

Development of a treatment strategy for acromegaly requires close involvement of the patient, endocrinologist, neurosurgeon and radiotherapist.

Lifelong regular review by an endocrinologist is needed so that:

• Adequacy of control of the acromegaly can be monitored
• Tumour regrowth or disease recurrence can be detected and treated early
• New deficiencies of other pituitary hormones caused by surgery or radiotherapy can be detected early and appropriate replacement therapy started

There are many physical signs and symptoms as untreated disease progresses. These include the development of oily, thick skin along with cysts and other benign growths, enlargement of the forehead, chin, nose, tongue and lips, increased space between teeth, arthritis and increased body hair. Growth hormone also has important but less obvious effects on the heart, pancreas, kidneys and upper airways and leads to enlargement of many internal organs.

The best way of monitoring GH oversecretion by the tumour is to do a blood test to check the level of insulin-like growth factor-1 (IGF-1 for short). IGF-1, a substance made in response to GH, is the actual hormone that produces many of the effects of GH in acromegaly.

Monitoring of complications caused by excess GH need to be followed up.

Sleep Apnoea: Enlargement of the tongue leads to a narrowing of the air passages and frequently results in choking and gagging during sleep. The disruption of sleep throughout the night results in daytime sleepiness, loss of mental concentration and chronic tiredness.

Colonoscopy: Acromegaly is also associated with an increased risk of neoplasms, particularly benign and malignant tumours of the colon.

HBA1c: A blood glucose test or a 3 monthly blood test to monitor diabetes mellitus.

Hypertension: Regular measurement of blood pressure.

Sore Joints and Swelling: Arthritis treatments and therapies to avoid permanent debility.

Blood Tests: An expected delayed side effect of radiotherapy is the development of deficiencies of some of the other pituitary hormones, which may occur as long as 10 years after treatment. Secretion of other pituitary hormones is checked by special endocrine tests of pituitary function. If deficiencies of any pituitary hormones are found, replacement treatment is commenced.

If untreated, acromegaly can have long-term consequences and diminishes the quality of life through cosmetic disfigurement, joint pains, headache and the effects of sleep apnoea. Hypertension (high blood pressure) and diabetes, which may develop as a result of acromegaly, can also reduce life expectancy. Therefore, continued monitoring and intervention may prevent irreversible changes associated with prolonged exposure to elevated growth hormone levels and may also result in life expectancy becoming normalised.
Do you have growth hormone deficiency? REAL 1

Consider Volunteering
If you have growth hormone deficiency and have not received any growth hormone treatment, or have not received any growth hormone treatment within the last 6 months (180 days), you may be eligible to take part in this clinical research trial.

You may qualify if you:
- Are between 23 and 79 years of age, both inclusive
- Have a confirmed diagnosis of growth hormone deficiency with either adult or childhood onset
- Have not received treatment with growth hormone or other growth factors within the last 6 months (180 days)

In the trial, a once weekly growth hormone treatment is compared to once daily growth hormone treatment and to placebo (inactive drug).

If you are interested and would like to have more information, please contact:

Royal Melbourne Hospital, VIC: Research Manager (03) 9342 7344
Eastern Clinical Research Unit, VIC: REAL 1 Research Nurse (03) 9094 9520
Keogh Institute for Medical Research, WA: REAL 1 Study Coordinator (08) 9346 2475
Royal North Shore Hospital, NSW: REAL 1 Study Coordinator (02) 9463 1864
Blacktown Hospital, NSW: REAL 1 Study Team (02) 9851 6073
Garvan Institute of Medical Research, NSW: Nurse Unit Manager (02) 9295 8231

The clinical research is conducted in collaboration with the pharmaceutical company Novo Nordisk A/S NN8640-4054 Ads, vers. 1.0 dated August 2014. UTN: U1111-1145-0211

**Newsletters 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

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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 February 2016

**Deadline:** 15 February 2016

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**Making a donation**

Australian Pituitary Foundation Ltd is the only national not-for-profit organisation dedicated to supporting and advocating for patients and families living with the effects of pituitary disease and disorders. You can help to sustain our services by making a donation. Please fill out the form below or go to www.pituitary.asn.au to make your gift online.

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