

OZGROW

The Australasian Paediatric Growth Hormone Database

ANNUAL REPORT

2005

Prepared in February 2006 by:

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On behalf of the

OZGROW Committee of the

Australasian Paediatric Endocrine Group (APEG)

LIST OF CONTENTS

		<i>Page</i>
1	BACKGROUND INFORMATION REGARDING OZGROW	3
1.1	Introduction and rationale	3
1.2	Outcomes	3
1.3	Summary	4
1.4	Structure of OZGROW	4
1.5	Process for OZGROW Research Projects	5
2	ACKNOWLEDGEMENTS	6
3	CURRENT STATUS OF THE OZGROW DATABASE	7
3.1	Access to data required for the OZGROW database	7
3.2	Data merging	9
4	ANNUAL SUMMARY 2005	11
4.1	Summary of diagnostic and auxological data on children receiving GH therapy in Australia and New Zealand	11
4.1.1	History of children who have received GH therapy in Australia and New Zealand	11
4.1.2	Children currently receiving GH therapy in Australia	13
4.2	Adult height studies	15
4.2.1	Study 1: Variability in height response to growth hormone treatment across diagnostic groups	15
4.2.2	Study 2: A comparison of published criteria for determining adult height in girls: Does the criteria used alter the determined height?	17
5	OTHER ACTIVITIES OF 2005	20
5.1	Presentations	20
5.2	Liaising with key stakeholders	21
6	DIRECTIONS FOR 2006	22

1. BACKGROUND INFORMATION REGARDING OZGROW

1.1 Introduction and rationale

Throughout the world, thousands of height restricted children are treated with growth hormone (GH). The main aim of GH treatment in children is to improve final height. As with any medical intervention, it is important that children receiving GH treatment are regularly monitored at the local level to determine if the treatment has improved the targeted outcome (i.e. height gain). It is also important to look at trends in patient outcomes at the broader national and international level to assess the overall benefit of the treatment for improving outcomes for the target population.

'OZGROW' is the name given to the national database designed to prospectively collect outcome data on children receiving GH throughout Australia and New Zealand. The concept of OZGROW was an initiative of the Australian Paediatric Endocrine Group (APEG).

In 2004, the OZGROW Advisory Committee of APEG appointed the position of OZGROW Research Team to the Children's Nutrition Research Centre (CNRC), which is located on site at the Royal Children's Hospital in Brisbane. The OZGROW Research Team consists of a 0.75 research position, currently shared by Pamela Dodrill and Lisa Atkin, and an overseeing role from the Director of the CNRC, A/Prof Peter SW Davies.

1.2 Outcomes

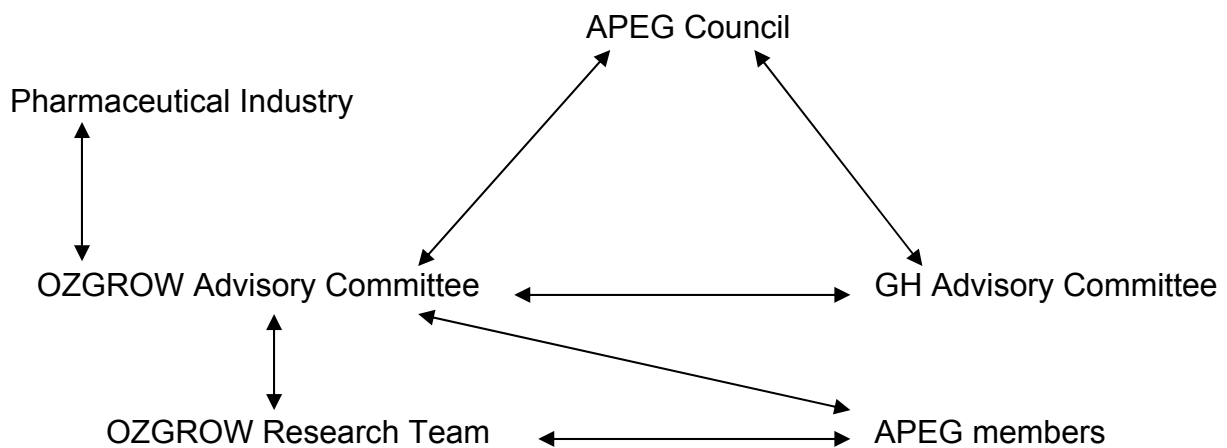
- The OZGROW Database currently holds data on the growth outcomes of over 5000 children who have received GH treatment.
- The OZGROW Research Team provides an annual report to APEG summarising diagnostic and auxological data on children receiving growth hormone in Australia and New Zealand.
- The OZGROW Research Team are also able to provide detailed reports on specific topics, such as adult height outcomes for children on GH, response to dosage of GH and complications of GH usage, as well as growth outcomes of children with specific disorders (e.g. Turner Syndrome, Russell Silver/ Prader Willi/ Noonan syndromes, chronic renal failure, or other indications for GH treatment).
- Practicing endocrine clinicians are encouraged to collaborate with the OZGROW Research Team to investigate topics of clinical importance.

1.3 Summary

- The OZGROW Research Team is currently involved in several ongoing research projects, which have resulted in many presentations and publications.
- Further research projects are expected.
- Collaboration between practicing endocrine clinicians and the OZGROW Research Team to investigate topics of clinical importance is encouraged.
- Research undertaken by the OZGROW Research Team has the potential to affect clinical practice in the area of paediatric endocrinology, both nationally and internationally.


1.4 Structure of OZGROW


The current management structure of OZGROW is as follows:



The process for collaboration between practicing clinicians, the OZGROW Advisory Committee, and the OZGROW Research Team is outlined in the diagram over leaf.

1.5 Process for OZGROW research projects

<p>Clinician has suggestion for research topic</p> 
<p>The clinician contacts the OZGROW Advisory Committee with a brief outline of their suggested research topic.</p>
<p>The OZGROW Advisory Committee contacts the OZGROW Research Team to pass on the clinician's suggestion and contact details.</p>
<p>The OZGROW Research Team contacts the clinician to discuss their suggested project. They agree on the level of involvement the clinician wishes to/ would be able to commit to (i.e. involvement in design, interpreting analysis, writing of papers, reviewing drafts of papers etc.).</p>
<p>The OZGROW Research Team and the clinician perform their allocated tasks, as agreed.</p>
<p>The OZGROW Advisory Committee are sent any draft papers to review prior to submission to journals.</p>
<p>Both the OZGROW Research Team and the clinician are listed as authors on any papers arising from the project.</p>
<p>All papers are published on behalf of the OZGROW Advisory Committee of APEG.</p>

<p>OZGROW Research Team has suggestion for research topic</p> 
<p>The OZGROW Research Team contacts the OZGROW Advisory Committee with a brief outline of their suggested research topic.</p>
<p>The OZGROW Advisory Committee forwards details of proposed project onto APEG members and asks if any clinicians are interested in being involved in the project.</p>
<p>The interested clinician contacts the OZGROW Advisory Committee or the OZGROW Research Team directly.</p>
<p>The OZGROW Research Team contacts the clinician to discuss the proposed project. They agree on the level of involvement the clinician wishes to/ would be able to commit to (i.e. involvement in design, interpreting analysis, writing of papers, reviewing drafts of papers etc.).</p>
<p>The OZGROW Research Team and the clinician perform allocated tasks, as agreed.</p>
<p>The OZGROW Advisory Committee are sent any draft papers to review prior to submission to journals.</p>
<p>Both the OZGROW Research Team and the clinician are listed as authors on any papers arising from the project.</p>
<p>All papers are published on behalf of the OZGROW Advisory Committee of APEG.</p>

2. ACKNOWLEDGEMENTS

The OZGROW Research Team would like to acknowledge the support and guidance of the OZGROW Advisory Committee of APEG:

- Dr Andrew Cotterill (Chair), Dr Cathy Choong, Dr Chris Cowell, Dr Wayne Cutfield, and Dr Kim Donaghue.

The OZGROW Research Team would also like to acknowledge the continuing financial support of the following companies:

- Eli-Lilly Australia Pty. Ltd.
- NovoNordisk Pharmaceuticals Pty. Ltd.
- Pfizer Australia Pty. Ltd.
- Sandoz Australia Pty. Ltd. (commencing 2006)
- SciGen Pty. Ltd.
- Serono Australia Pty. Ltd.

In addition, the OZGROW Research Team would also like to thank the clinical teams at the following growth centres for their time and effort in the collection and entering of data, and their ongoing support of work conducted by OZGROW:

- Adelaide Women's and Children's Hospital
- Cairns Base Hospital
- Dr Mike Thomsett's Private Clinic, Brisbane
- Liggins Institute, Auckland, New Zealand
- Mater Children's Hospital, Brisbane
- Monash Medical Centre, Melbourne
- Princess Margaret Hospital, Perth
- Royal Children's Hospital, Brisbane
- Royal Children's Hospital, Melbourne
- Royal Hobart Hospital
- Sydney Children's Hospital
- The Children's Hospital at Westmead
- The John Hunter Hospital, Newcastle
- Commonwealth Department of Health and Aging (DoHA), Canberra

3. CURRENT STATUS OF THE OZGROW DATABASE

3.1 Access to data required for the OZGROW database

History of data collection

Prior to 2000, data on children receiving GH treatment within Australia were collected on a purpose-built OZGROW database, which operated on a DOS platform. Major growth centres entered data regarding their patients onto a local copy of the database. Every month data were sent on disc to the national OZGROW database, which at that time was located at the Children's Hospital at Westmead. The national database was then 'recreated' each month from the latest data sent from each centre.

Concerns regarding Y2K incompatibility resulted in the DOS database being abandoned. However, to their credit, most growth centres found other database platforms to use to enter and store their growth data. Some centres developed their own database platforms (i.e. the Children's Hospital at Westmead, Sydney Children's Hospital). Other centres chose to use databases developed by either the Dutch Growth Foundation or by one of the pharmaceutical companies who supply GH. Initially, most centres used the same database (KGS). More recently, centres have commenced using a variety of different database platforms (e.g. MeGHA, NordiNet, KGS, Growth Analyser).

Current data collection

Currently, OZGROW receives data from the following sources:

- The Children's Hospital at Westmead
 - Data supplied from a database unique to this hospital
- Sydney Children's Hospital
 - Data supplied from a database unique to this hospital
- Other major growth centres within Australia
 - Data supplied from a combination of database systems developed by either the Dutch Growth Foundation (Growth Analyser) or various pharmaceutical companies (currently: KGS, MeGHA, Nordinet)
- Liggin's Institute, New Zealand
 - Data supplied from a database developed by a pharmaceutical company (currently KGS)
- DoHA Canberra
 - Data supplied from a database unique to this department

In 2005, data retrieval from many of the growth centres within Australia and New Zealand has proven problematic for a number of reasons:

- Many centres have had problems entering data into their database, as well as downloading information from their database to send to OZGROW.
- Many centres have recently changed or are considering changing to different database platforms.
- Currently, some centres have patient data spread over different databases, or periods where patient data has not been entered into any database.
- Many of the database programs supplied by pharmaceutical companies are currently in the process of being updated/ redeveloped.

The OZGROW Research Team is not in a position to endorse any particular database or make recommendations to centres regarding their choice of database. However, in order to assist growth centres to obtain improved product/ service, the OZGROW Research Team (in consultation with major growth centres) formed a list of many essential and desirable features of a GH patient database, which was provided as a reference to the various pharmaceutical companies who design and supply such databases. Clinicians have been advised that the choice of database should be a local decision, and should be made purely on what best suits the local clinicians and researchers at each of the various growth centres.

Data retrieval from Department of Health and Aging (DoHA) in Canberra

The OZGROW Research Team has recently invested much time and effort in negotiating access to the data stored by DoHA in Canberra from the *Application for Growth Hormone* and *Growth and Treatment* record forms submitted by clinicians. This information has been used to augment information provided directly from centres. Special thanks are owed to Kim Oanh-Nguyen and Briar Carr for their assistance with obtaining this data.

Ongoing meetings/ visits with DoHA will be required to maintain and improve this source of data, in terms of:

- Information requested on *Application for Growth Hormone* and *Growth and Treatment* record forms
- Information entered into the database and stored electronically by DoHA

In addition, ongoing liaison with growth centres will be required to improve the quality of data sent into DoHA. For example:

- It is apparent that many of the growth centres around Australia are no longer using OZGROW diagnosis codes on the DoHA record forms. It appears that some centres are currently using alternate lists of diagnosis codes from patient databases supplied by pharmaceutical companies, rather than the OZGROW diagnosis codes. It also appears that some centres are currently not using diagnosis codes at all, and provide a written description of the diagnosis instead.
- To allow more accurate conclusions to be drawn from the data, it is vital to re-establish a uniform set of diagnosis codes to be used across the various growth centres in Australia. The OZGROW Research Team, along with the OZGROW Advisory Committee (chaired by Dr Andrew Cotterill) and the Growth Hormone Advisory Committee (chaired by Dr Christine Rodda) have reviewed these various options and have come to the consensus that it is essential for future research purposes that all growth centres use OZGROW diagnosis codes only on future DoHA record forms.
- A paper copy of the OZGOW codes will be mailed to all major growth centres to ensure that all sites have access to the codes. In addition, an electronic copy of these codes will soon be available on the APEG website at: www.racp.edu.au/apeg/ to assist clinician access to this information.

3.2 Data merging

Due to the diverse format of databases used for storing data across Australasia, there has also been considerable time and effort spent in investigating possible platforms for storing and analysing the complete national OZGROW data set as a whole, as opposed to maintaining data on separate systems. Whilst this is still to be fully resolved, three main options are available.

The three options are:

- i) To continue with the collection of data in the centres as it currently stands, and either use a developed database, such as Growth Analyser, to import all the different data formats into one database, or consult with a database expert and develop OZGROW's own bespoke program, that can merge the

different data types. Much time has been spent investigating this option, and this has proven to be a very difficult and time-consuming operation.

- ii) To rely more heavily on the GH data supplied directly from the DoHA in Canberra, so that all data are in one format. This would require changes to the forms that are sent to Canberra, as well as improvements in the way that DoHA enters and stores data. This option is being investigated.
- iii) To introduce a 'new' program in each centre for the specific collection of growth hormone data. (This is the least favourable option, but one that could be considered).

Until this decision is finalised, data from various sources remains on separate systems. Therefore, at present, before any data analysis can occur, the relevant raw data needs to be extracted from the various database platforms, synchronised, merged, and then stored. Clearly this is a labour-intensive and time-consuming process. Therefore, ongoing investigation into a more efficient way of collecting/ storing data will continue.

4. ANNUAL SUMMARY 2005

This section of the report is submitted as part fulfilment to the requirements specified in the OZGROW Research Team tender and subsequent funding contract; specifically to:

- i) Provide an annual report summarising diagnostic and auxological data on children receiving growth hormone in Australia and New Zealand.
- ii) Provide a detailed report on one of the following (in rotation):
 - a. Turner Syndrome (2004)
 - b. Adult Height (2005)
 - c. Response to dosage of GH and complications of GH usage
 - d. Russell Silver/ Prader Willi/ Noonan syndromes or Chronic renal failure or 'Other Indications'.

4.1 Summary of diagnostic and auxological data on children receiving GH therapy in Australia and New Zealand

4.1.1 History of children who have received GH therapy in Australia & New Zealand through government funded programs

DoHA records indicate that 4701 children have been registered as having received GH therapy through the government funded system in Australia. Due to privacy laws, which ensure each patient's right to refuse to allow their data to be made available for research purposes, OZGROW currently has access to data on only 4140 of these patients. This represents 88% of the total population of patients who have received GH therapy via the government funded system in Australia. OZGROW also has access to information regarding 595 patients from New Zealand who have received GH therapy. This represents all patients who have been registered as having received GH therapy through the government funded system in New Zealand. Currently, OZGROW does not receive information regarding children receiving privately funded GH therapy.

The following statistics relate only to the patients who:

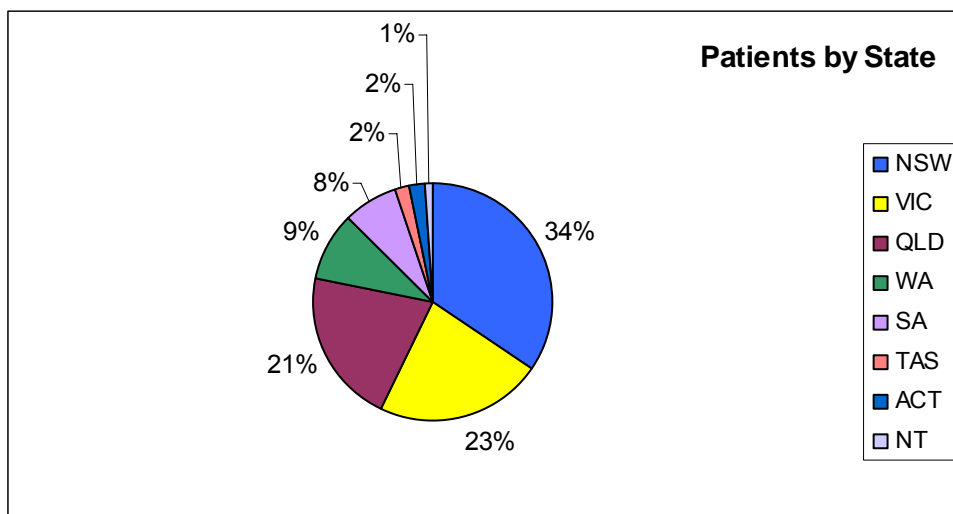
- (a) OZGROW has access to information on, and
- (b) who have commenced GH therapy

(Note: Due to difference in the type of data stored on databases in different growth centres, previous OZGROW reports may have included data on children who were being

monitored because of short stature, but who had not commenced any GH therapy, in addition to children who had actually received GH therapy.)

Demographics of children who have received GH therapy in Australia and New Zealand

- Gender of patients who have received GH therapy = 55.6% male (M:F= 1.25 :1)
- Average age at commencement of GH therapy = 8.75 years (0-19)
 - >75% by 12 years
- Within Australia, >75% of patients who have received GH therapy originate from NSW, VIC, QLD



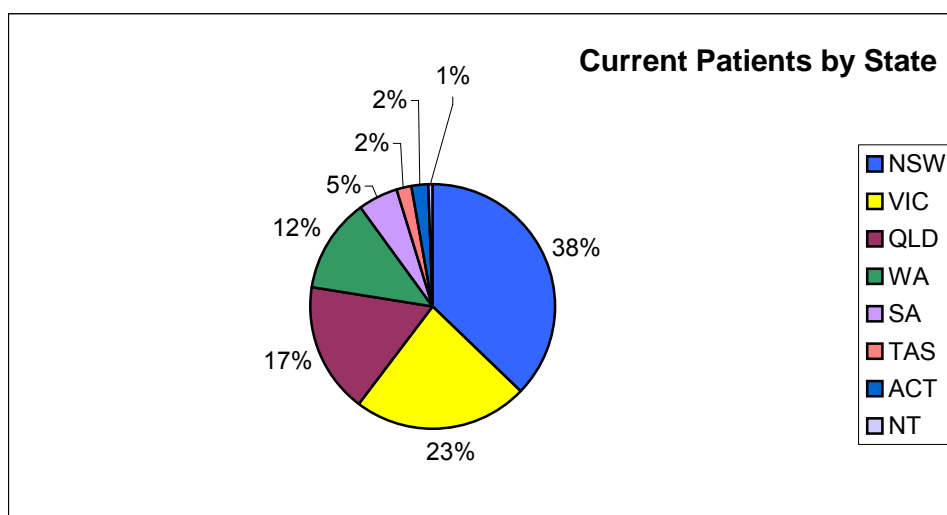
GH therapy over time

- Number of children commencing GH therapy in different decades
 - 304 children commenced GH therapy in the 1980s (average 30 per year)
 - 2372 commenced GH therapy in the 1990s (average 237 per year)
 - 1464 have commenced GH in the 6 years since January 2000 (average 244 per year)
- Gender of children commencing GH therapy in different decades
 - 1980s – 63.2% Male (M:F= 1.5 : 1)
 - 1990s – 56.6% Male (M:F= 1.3 : 1)
 - 2000-present – 52.5% Male (M:F= 1.1 : 1)
- Average age at commencement of GH therapy in different decades
 - 1980s – 8.77 years
 - 1990s – 8.93 years
 - 2000-present – 7.45 years

4.1.2 Children currently receiving GH therapy in Australia and New Zealand through government funded programs - 2005

Demographics of children currently receiving GH therapy in Australia and New Zealand

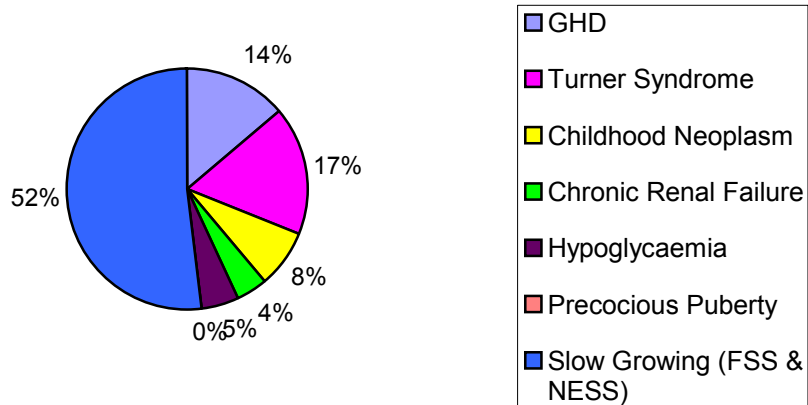
- Number of children currently receiving GH therapy in Australia = 1299.
- Number of children currently receiving GH therapy in New Zealand = 197.
- Gender of patients currently receiving GH therapy = 53.2% Male (M:F= 1.15 : 1).
- Average age at commencement of GH therapy = 7.06 years.
 - >75% by 10 years.
- Within Australia, >75% of patients currently receiving GH therapy originate from NSW, VIC, QLD (see diagram). There are an increasing proportion of patients from WA also.



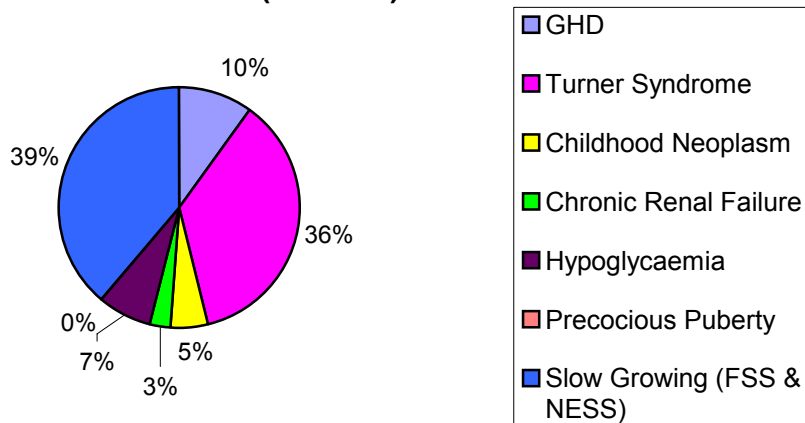
Reason for commencement of GH therapy in Australia

- Criteria for receiving GH therapy via the government funded GH program are listed in the DoHA document titled "Guidelines for the Availability of Human Growth Hormone (hGH) as a Pharmaceutical Benefit".
- >50% of all current patients in Australia were commenced on GH therapy under the criteria of 'slow growing' (i.e. Height <1st percentile according to Centres for Disease Control growth data) (see Figure).
 - This was the most common treatment criteria in males (64%).
 - This was also the most common treatment criteria in females (39%), closely followed by Turner Syndrome (36%).

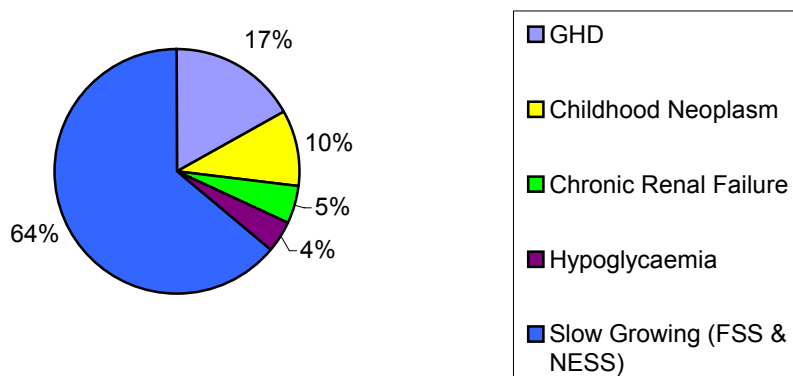
Reason for Commencement of GH Therapy



Reason for Commencement of GH Therapy (Females)



Reason for Commencement of GH Therapy (Males)



4.2 Adult Height Studies

4.2.1 (Study 1)

Variability in height response to growth hormone treatment across diagnostic groups.

Introduction

In Australia and New Zealand, human growth hormone (GH) has been available since the 1980s to treat children who are short and slowly growing due to a range of conditions. The optimisation of GH therapy to improve adult height (AH) continues to be a challenge in the clinical care of these patients who represent a spectrum of GH status from GH deficiency through to GH resistance. To assist in designing GH treatment regimens we sought to provide diagnosis specific AH data, and to examine inter-individual variation in response to therapy.

Methods

The OZGROW database, a national registry of all children receiving GH in Australia and New Zealand, provided retrospective data for analyses. Patients were selected if they had reached AH, defined as growth velocity <1cm/year, or bone age (Greulich & Pyle) ≥ 17 years for boys and ≥ 15 years for girls. The 196 children identified were categorised into the following diagnostic groups: idiopathic GH deficiency (GHD), GH deficiency post-neoplasm (PN), idiopathic short stature (ISS), Turner syndrome (TS), and non-endocrine short stature (NESS).

Height standard deviation scores (Ht SDS) were calculated for all children at the start of GH treatment and at AH using Australasian population reference ranges¹; Turner specific reference data were used for children with TS². Variability in response to GH was assessed by calculating the coefficient of variation (CV) of change in Ht SDS (AH SDS - Ht SDS at start of GH).

Results

GH treatment improved adult height for all diagnoses, with PN children displaying on average the smallest increase in Ht SDS and GHD children the most substantial. There was considerable variation in response to GH therapy within each diagnostic group. This dispersion ranged from a CV of 46.2% in the GHD group to 210.5% in the PN group. Data are shown in Table 1 (overleaf).

Table 1. Variability of change in Ht SDS by diagnosis

Diagnosis	N	Δ Ht SDS		
		Mean	SD	CV (%)
GHD	28	2.49	1.15	46.2
PN	44	0.65	1.38	210.5
ISS	39	0.86	0.94	109.3
TS	47	1.26	0.74	58.9
NESS	38	0.99	0.99	98.7

Conclusion

These data will be of use to clinicians when treating children with GH as they provide information on the change in Ht SDS to AH and the variability of linear growth response for selected diagnoses. The highly variable reaction to GH found in PN patients may be due to a depressed response seen in certain types of neoplasia^{3,4} and in patients who have received spinal irradiation⁵. These data may also be helpful in forming realistic expectations of treatment outcome for the patient and family.

References

1. National Center for Health Statistics. NCHS growth charts. Monthly Vital Statistics Report 1976;25 Supplement (HRA):76-1120. Rockville MD: Health Resources Administration.
2. Ranke MB, Stubbe P, Majewski F, Bierich JR. Spontaneous growth in Turner's syndrome. *Acta Paediatrica Scandinavica (Supplement)* 1988;343:22-30.
3. Ranke MB, Price DA. Growth hormone treatment in children with malignant cranial tumours in KIGS. In: Ranke MB, Wilton P, editors. *Growth hormone therapy in KIGS: 10 years' experience*. Heidelberg: Johann Ambrosius Barth Verlag, 1999: 159-74.
4. Stahnke N. GH treatment in children in remission from leukaemia and lymphoma in KIGS. In: Ranke MB, Wilton P, editors. *Growth hormone therapy in KIGS: 10 years' experience*. Heidelberg: Johann Ambrosius Barth Verlag, 1999: 175-88.
5. Adan L, Sainte-Rose C, Souberbielle JC, Zucker JM, Kalifa C, Brauner R. Adult height after growth hormone (GH) treatment for GH deficiency due to cranial irradiation. *Medical and Pediatric Oncology* 2000 Jan;34(1):14-9.

4.2.2 (Study 2)

A Comparison of Published Criteria for Determining Adult Height in Girls: Does the Criteria Used Alter the Determined Height?

Introduction

At least 6 different rules to determine the timing of adult height (AH) for girls have been used in the literature (1-6). The aim of this study was to assess whether, in the same population, different rules for determining AH would produce the same outcome.

Methods

Population: Data on Australian and New Zealand girls receiving GH treatment were accessed from the OZGROW database. Girls were included in the analysis if data regarding their standing height was available, along with data on at least one of the following variables: height velocity, chronological age, and bone age. All girls in the database had bone age determined using the Greulich and Pyle method.

Procedure: Six different rules for determining the timing of adult height for girls were extracted from the literature (see Figure 1). Each rule was applied to the data set to determine the value for adult height that they would yield.

Figure 1: Published rules for determining the timing of adult height

1. Last measured height after CA > 13.5yr (Chernausek et al, 2005)
2. BA > 15yr and HV < 1cm/yr over 1 year (Pasquino et al, 2005)
3. BA > 14yr or HV < 2cm/yr over 1 year (Buchlis et al, 2005)
4. BA ≥ 14yr and HV < 2cm/yr over 1 year (CGHAC, 2005)
5. BA ≥ 15yr or HV ≤ 2cm/yr over 1 year (Carel et al, 2003)
6. BA ≥ 15yr and HV < 1.5cm/yr over 6 months (Lin-Su et al, 2005)

In 5 of the 6 rules, the variables used to determine when adult height occurred were bone age and/ or height velocity. The values of these variables differed in the different rules (see Figure 2). The different values for both the BA criteria and HV criteria in the published rules were individually applied to the data set to determine the value for adult height that they would yield.

Figure 2: Variables used in published rules for determining the timing of adult height

BA	<ul style="list-style-type: none"> • ≥ 14yr • > 14yr • ≥ 15yr • > 15yr
HV	<ul style="list-style-type: none"> • ≤ 2cm/year • < 2cm/year • < 1.5cm/year • < 1cm/year

Statistical analysis: Independent-groups ANOVAs were used to compare adult height values when using the different published rules, as well as the various BA criteria and HV criteria. Post-hoc analyses were performed using the LSD method.

Results

ANOVA found no statistically significant difference between the value for girls' AH when determined using the various rules $F(5,3148)=0.960$, ($p=0.441$). Post-hoc analyses revealed no significant differences between AH determined by any of the individual rules. Subsequent ANOVAs found no significant difference between the value of girls' AH when determined using the various BA criteria $F(3,136)=0.886$, ($p=0.450$) or HV criteria $F(3,2084)=0.265$, ($p=0.851$). Post-hoc analyses revealed no significant differences between AH determined by any of the BA or HV criteria.

The greatest (and, thus, most accurate) value for AH in girls was obtained using the criteria $BA > 15y$. Compared to this figure, the values obtained using the AH rules underestimated AH by an average of 2.2cm. Similarly, the various HV criteria and the other BA criteria underestimated AH by an average of 2.1 and 2.3cm respectively.

Discussion

No *statistically* significant differences were found in the AH values obtained using the various rules for determining AH, or the various individual BA and HV criteria. However, using the criteria $BA > 15y$ produced the greatest value for AH. The AH rules and the various HV criteria and other BA criteria underestimated this AH value by an average of 2.1-2.3cm. Such a difference would be of *clinical* significance. In addition, a difference of

this magnitude in research findings could alter the perception of the usefulness of GH treatment.

Conclusion

Statistically similar values for AH are obtained using any of the rules for determining AH, or the various BA and HV criteria used in these rules. However, in cases where girls can not be followed to >15 years BA, it has to be acknowledged that the assumed AH is unlikely to be the girl's actual AH.

References:

1. Chernausek S, Attie K, Cara J, Rosenfeld R, Frane J. (2005). Growth Hormone Therapy of Turner Syndrome: The Impact of Estrogen Replacement on Final Height. *Journal of Clinical Endocrinology and Metabolism*, 87 (7), 2439-2445.
2. Pasquino A, Pucarelli I, Roggini M, Segni M. (2005). Adult Height in Short Normal Girls Treated with Gonadotropin-Releasing Hormone Analogues and Growth Hormone. *Journal of Clinical Endocrinology and Metabolism*, 85 (2), 619-622.
3. Buchlis J, Irizarry L, Crotzer B, Shine B, Allen L, Macgillivray M. (2005). Comparison of Final Heights of Growth Hormone-Treated Vs. Untreated Children with Idiopathic Growth Failure. *Journal of Clinical Endocrinology and Metabolism*, 83 (4), 1075-1079.
4. The Canadian Growth Hormone Advisory Committee (2005). Impact of Growth Hormone Supplementation on Adult Height in Turner Syndrome: Results of the Canadian Randomized Controlled Trial. *Journal of Clinical Endocrinology and Metabolism*.
5. Carel J-C, Chatelain P, Rochiccioli P, Chaussain, J-L. (2003). Improvement in Adult Height after Growth Hormone Treatment in Adolescents with Short Stature Born Small for Gestational Age: Results of a Randomized Controlled Study. *Journal of Clinical Endocrinology and Metabolism*, 88 (4), 1587-1593.
6. Lin-Su K, Vogiatzi M, Marshall I, Harbison M, Macapagal M, Betensky B, Tansil S, New M. (2005). Treatment with Growth Hormone and LHRH Analogue Improves Final Adult Height in Children with Congenital Adrenal Hyperplasia. *Journal of Clinical Endocrinology and Metabolism*.

5. OTHER ACTIVITIES OF 2005

5.1 Presentations:

- Written presentations
 - Articles
 - RA Abbott, L-M Atkin, and PSW Davies. Predicting adult height in Turner syndrome. Eur. J. Endocrinol., Jun 2005; 152: 917.
 - Articles (in preparation for submission)
 - Turner syndrome (2)
 - *Growth hormone treatment in Turner syndrome: Effect of four years treatment in young girls* (RA Abbott, L-M Atkin, PMM Dodrill, PSW Davies)
 - *Growth hormone treatment in Turner syndrome: Effect of dosage after three years of treatment* (L-M Atkin, RA Abbott, PMM Dodrill, PSW Davies)
 - Final Height (3)
 - *A comparison of published criteria for determining adult height in girls: Does the criteria used alter the determined height?* (PMM Dodrill, L-M Atkin, PSW Davies)
 - *Variability in height response to growth hormone treatment across diagnostic groups* (L-M Atkin, PMM Dodrill, PSW Davies)
 - *Adult height after growth hormone therapy – The OZGROW experience* (M Wang, LE Bath, GA Werther, CT Cowell, PMM Dodrill, L-M Atkin, PSW Davies)
 - Clinician queries
 - Three (3) queries have been received from clinicians. Relevant data were extracted from the database and provided to the requesting clinicians.
 - Pharmaceutical company queries
 - One (1) query has been received from a pharmaceutical company. Relevant data was extracted from the database and analysed. Copies of the results were provided to all of the various pharmaceutical companies who distribute GH in Australia.

- Oral presentations
 - Conference posters
 - ESPE 2005 (2)
 - *Growth hormone treatment in Turner syndrome: Effect of four years treatment in young girls* (RA Abbott, L-M Atkin, PMM Dodrill, PSW Davies)
 - *Growth hormone treatment in Turner syndrome: Effect of dosage after three years of treatment* (L-M Atkin, RA Abbott, PMM Dodrill, PSW Davies)
 - Endocrine Society 2006 – submitted (2)
 - *A comparison of published criteria for determining adult height in girls: Does the criteria used alter the determined height?* (PMM Dodrill, L-M Atkin, PSW Davies)
 - *Variability in height response to growth hormone treatment across diagnostic groups* (L-M Atkin, PMM Dodrill, PSW Davies)
 - Other oral presentations
 - Winter Endocrine Symposium, South Brisbane 2005
 - *The National OZGROW Database*
 - Serono Clinical Nurse Research Day 2005
 - *Update on the OZGROW Database*
 - Pfizer Clinical Nurse Research Day 2005
 - *Update on the OZGROW Database*

5.2 Liaising with Key Stakeholders:

- OZGROW Advisory Committee
 - Monthly face-to-face meetings between the Chair of the OZGROW Advisory Committee and the OZGROW Research Team
 - Quarterly teleconferences between the OZGROW Advisory Committee and the OZGROW Research Team
- DoHA Canberra
 - 2 visits to Canberra to negotiate access to data held by the DoHA relating to patients receiving GH therapy in Australia

- Growth Centres
 - Visits to the Children's Hospital at Westmead and the Sydney Children's Hospital to investigate access to data held on hospital databases relating to patients on GH therapy

6. DIRECTIONS FOR 2006

The major goals for the OZGROW Research Team in 2006 are to:

- Continue to collect data for the OZGROW database, both:
 - Directly from growth centres
 - Via DoHA, Canberra.
- Continue to investigate options for merging patient data provided in different formats.
- Continue with growth analyses on data within the OZGROW database.
Specifically to:
 - Complete research articles currently in preparation for publication
 - Continue with growth studies recently commenced
 - Commence new growth studies.