

Welcome ! Welcome to the first ever issue of info, the quarterly newsletter for HYPOHH members ! Yes, it is here at last and I still can't quite believe it myself yet... True, there will be nothing as exciting as an exotic holiday for two in the sun-soaked Bahamas to be won, but don't let that put you off. What info does promise you though is to keep you informed of any news relating to HYPOHH's recent activities, interesting articles and news features.

In this issue, we shall start with features on the first HYPOHH Open Day staged in London in July last year and the Inaugural Conference of The Pituitary Foundation held only a few weeks ago in Bristol. And for all you 'surfers' out there, you can also find all about how the Internet has helped HYPOHH reach out to fellow sufferers all around the world. Finally, I have invited Phiroze Neemuchwala, the psychotherapist whom many of you met at the Open Day last year, to write an article on how the difficulties of coming to terms with delayed or absent puberty can affect self-esteem.

I hope that you find the next few pages an informative read. If you have any comments and suggestions about the newsletter's style, content, features or anything else you would like to see improved or included in a future issue of info, please feel free to write to me at the address given on page 4.

Mark Saunders

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1st HYPOHH Open Day On 12th July 1997 the first national meeting of HYPOHH was held at the Royal Free Hospital, London. I was slightly nervous at first, as this was the first ever meeting of its kind anywhere in the world, but thankfully, it was a great success.

HYPOHH was formed in late 1994 and came under the PitPat umbrella a few months later. It currently has more than 80 members, both in the UK and overseas, including Germany, the Netherlands, USA, Canada, Singapore, Australia, New Zealand and Taiwan. Around 50 of these members are patients and their relatives, most of whom have Kallmann's syndrome. Kallmann's syndrome is a form of hypogonadotrophic hypogonadism characterised by an absence of GnRH, a hormone normally released by the hypothalamus. Sufferers fail to go through puberty unless they are given sex hormone replacement therapy and in addition have no sense of smell (anosmia). The remaining 30 HYPOHH members are not patients, but they do have a professional interest in hypogonadotrophic hypogonadism. These include those employed by the pharmaceutical industry, endocrinologists and other specialists.

Four years ago, I did not believe that I would ever meet another person with Kallmann's syndrome, let alone give a presentation to a room full of fellow Kallmann's patients. Like so many sufferers, I found it difficult for many years to find information about my condition and to share my problems with others, mainly because the disease is so uncommon. After all, only 1 in 10,000 men and 1 in 70,000 women are estimated to be affected by the disease.



Saturday, July 12th 1997 - The Open Day was a great success; over 30 people (patients, their families, specialists and professional counsellors) travelled to London especially for the event to attend a series of informal seminars and to meet fellow sufferers of Kallmann's syndrome (and related conditions) for the first time.

The meeting was very well-attended, with members travelling down from as far away as Hull and Merseyside ! It was very useful for me to put faces to the names of those people to whom I have spoken on the telephone over the last three years and a number of people have told me that they found it valuable to meet others who had had similar experiences to themselves. Kallmann's syndrome can be a very isolating condition, particularly for teenagers trying to come to terms with all the normal pressures of adolescence as well as failing to develop the same physical and sexual characteristics normally experienced during puberty, so I was particularly pleased to see that several teenagers attended the Open Day.

The meeting and HYPOHH itself would not have been possible without the support and enthusiasm of Dr Pierre Bouloux and Dr Richard Quinton, both of whom were on hand to answer medical queries and to discuss

"Kallmann's syndrome can be a very isolating condition, particularly for teenagers"

the types of treatment on offer to patients. I would also like to thank Mr Phiroze Neemuchwala, who gave a very interesting talk about the psychological problems that many Kallmann's patients may experience when attempting to come to terms with their condition.

Due to 'public' demand, there will be a 2nd HYPOHH Open Day which will be held on Saturday, July 25th 1998 at the Royal Free Hospital (more details on page 4). I look forward to seeing you all there.

Mark Saunders

HYP0HH Update The past 12 months have been very busy ones for HYP0HH. Read all about what we've been up to...

- **Booklet on Kallmann's Syndrome**

April 1997 saw the publication of the illustrated booklet on Kallmann's syndrome ("Understanding Kallmann's Syndrome - Your Questions Answered"), the first ever such publication aimed specifically at patients suffering from this rare disease. If you do not have a copy, please write to HYP0HH at the address given on page 4. There is no charge.

The booklet has also attracted plenty of interest from endocrinologists and patients from all corners of the globe; German and Chinese (Taiwanese) translations of the booklet will be published within the next few months.

- **1st HYP0HH Open Day**

You have already read about this on page 1 of this newsletter. If you were not able to make it to our first Open Day in July last year, do not worry. There will be another one on Saturday 25th July.

- **HYP0HH in the Multimedia Age**

For those of you who are unsure about what multimedia actually is, let me explain. Multimedia combines a number of different media (sounds, animations, film clips and text) for display on a computer screen. Rather than replacing the good old fashioned book, multimedia actually complements conventional forms of media. In fact, some people refer to multimedia CD-ROMs as 'electronic books' and that is a fairly accurate description. However, you can do things with multimedia that would not be possible with a book.

If a multimedia presentation is well-designed, it is very easy to use, even by people with no or little knowledge of computers. An ideal environment for multimedia is the doctor's surgery or a hospital waiting room. Doctors often have limited time available to spend with patients and consequently, many patients' questions are left unanswered. Patients often want to gain a more thorough understanding of their particular condition but this is not always possible or practical in an hospital environment. The beauty of multimedia is that it is 'interactive'; i.e. the patient dictates the pace of learning about their particular ailment by browsing through 'pages' on the computer screen, a bit like flicking through the pages of a book but with animations and film clips along the way. All around the world, many thousands of patients suffering from all kinds of diseases have benefitted from interactive multimedia. HYP0HH has been involved in creating patient-targeted multimedia projects for the last two years and is now working on a CD-ROM on 'Hormones &

Puberty'. If you would like to have a copy of one our presentations and you own or have access to a PC (Apple Mac or IBM-compatible), write to us.

- **HYP0HH on the Internet**

Our web site HYP0HH.net is still under construction and is scheduled to be online in the summer. We do however have an e-mail address, HYP0HH@aol.com.

In the past five months alone, HYP0HH has managed to contact around two dozen people with Kallmann's syndrome in the

USA, Canada and Singapore via the Internet and e-mail. Dan Brown, an American Kallmann's syndrome sufferer runs an online patient support group and HYP0HH has worked closely with him to get it up and running. It is our plan to set up a HYP0HH (USA) in the near future and there is certainly no shortage of willing volunteers. Anybody interested in subscribing to Dan's e-mailing list should contact him directly on his e-mail address: brown@greenonions.com.

Pituitary Foundation (PitPat) Inaugural Conference

Following its national launch in November 1994, membership of The Pituitary Foundation has grown phenomenally from 250 to 4,500. The charity's Inaugural National Conference was held in Bristol on Saturday 18th April with around 350 delegates attending.

As HYP0HH comes under the 'umbrella' of The Pituitary Foundation, we were there too. After all, it is largely due to the experience of The Pituitary Foundation and its large network of pituitary patients and contacts in both the pharmaceutical and healthcare industries that HYP0HH's membership has grown as rapidly as it has.

The day's proceedings started with a warm welcome from the charity's Chairman, Professor Stafford Lightman, followed by a series of highly informative presentations from some of the UK's leading specialists on pituitary diseases. In the afternoon, the conference was divided into a number of small interactive 'workshops' on specific disorders, giving patients the opportunity to ask the experts about acromegaly, diabetes insipidus, Cushing's disease and

patient/consultant communication. Of particular interest to sufferers of hypogonadotropic hypogonadism were the 'workshops' on hypopituitarism, infertility, the psychological/psychiatric problems associated with pituitary disorders and self-image.

There were three other HYP0HH members at the conference apart from myself and my wife Lorna, all of whom I have written to and spoken to on the phone several times over the past year but whom I had never actually met before. My only regret is that because we were so absorbed in the day's events, we were unable to spend more time sharing our experiences. I hope we can make up for that another time.

I enjoyed the conference very much, not only because it was so well organised, but also because it just proves that there are many patients out there who are hungry for more information. All credit must go to Rachel, Sue, Gail and all the other volunteers of The Pituitary Foundation for making the conference so worthwhile.

Mark Saunders



Saturday, April 18th 1998 - In one of the day's 'workshops', Dr Trevor Howlett of the Leicester Royal Infirmary gave a very interesting lecture on the causes and symptoms of hypopituitarism and how it can be treated. Other workshops dealt with infertility, psychological/psychiatric problems associated with pituitary disorders and patient/consultant communication.

Towards a Theory of Self-Esteem

- a psychotherapist's perspective

I met Mark Saunders last year at the first HYPOHH Open Day at the Royal Free Hospital, when the psychiatrist who was supposed to be on the panel of experts had to drop out at the last moment. When he asked me to take his place my first response was to say "What do I know about Thallmann's syndrome?" After my colleague had corrected my medical terminology he admitted that he knew nothing about it either and suggested that I'd be as good as anyone on the panel, even though I am a psychotherapist and not a psychiatrist.

Despite my misgivings about what I might be able to contribute to a conference of patients of an endocrinological disorder, I agreed to take part. I discovered during the day that although hormone deficiencies of this nature do not affect brain development, they certainly do affect self-esteem, self image, self-confidence and sexual self-concept. Some of the many questions that were addressed to me did indicate that it was indeed appropriate that a psychotherapist was present rather than a psychiatrist. For those of you who are not clear about the difference between the two, a psychiatrist is a doctor who is specially trained to diagnose and medicate mental illness. A psychotherapist is a non-medical professional who is trained to

understand how a person's early life can result in them having a limited ability to understand how a person's early life can result in them having a limited ability to enjoy later life. A psychiatrist tends to see the patient once every few months to monitor how the medication is working. A psychotherapist sees the client once or twice a week for several months in order to work through how early life has resulted in dysfunctional ways of approaching life which affect our happiness.

When Mark got in touch last month and asked me to write an article for the first Kallmann's Newsletter, I was unsure how to approach this opportunity, so I have decided to ask you, the readers, how I might be able to help. Rather than assuming that I know what you would like to hear about, I am using this chance to ask you to write to me and tell me what issues you would like me to address in subsequent articles. Let me know what kind of problems, dilemmas, crises and situations you have had to face and perhaps from this will flow a series of truly useful articles.

For this first one I have written a very general piece on self-esteem which I hope will be of some use to some of you.

TOWARDS A THEORY OF SELF-ESTEEM

1. Self respect is to do with how much we honour the self as a unique, valuable person. It is shown by the warmth, friendliness and fair

treatment that we extend to ourselves. If our parents, teachers or fellow pupils hardly treated us in this way, we won't know how to do it. Often our self-esteem is influenced by us transposing the reality of physical abnormality onto our self-worth.

2. This honouring of the self needs to be consistently nurtured in the home environment during the first 16 years, at least. If it is not, the child will make judgments about itself based on what it sees and hears. If we are treated as if we are worthless, we will start believing that we are worthless, even if the word is never actually spoken. If our schools fail to provide adequate encouragement, respect and support we will conclude, painfully and angrily, that we do not have value or deserve respect.

3. Even if self respect is adequately fostered at home, it can become damaged after traumatic experiences, or physical conditions after which, for example, our mind tells us that we are somehow damaged, tainted or wrong. These traumas can come from the outside world, like a failed exam or relationship breakup, or they can be generated from the inner world, as in the case of people who feel anger towards a sibling or a parent and then call themselves wicked, evil and bad. In some families, where "difficult" personalities surround us, it is important to remember that feelings of anger and hate are understandable and inevitable. IT DOES NOT MEAN THAT WE ARE BAD PEOPLE, JUST THAT WE FELT HURT OR FRIGHTENED AND THEN FELT ANGRY AND HATEFUL.

4. As we grow up, the mind creates a special collection of cruel names that other people have called us and that we have believed are true. THE ONLY INSULTS THAT WILL HURT US ARE ONES THAT WE ALREADY BELIEVE ARE TRUE. These are names such as "stupid, evil, ugly, worthless, selfish, bad, wrong, useless, cold, idiot, failure, tainted, inadequate, imperfect etc. These names are cruel, unfair exaggerations. They may have had a grain of truth but nothing more.

5. Because it is very painful to live under the weight of these names, we develop ways of being that try to prove that the opposite is true, for example, people who secretly believe that they are cowardly failures may well become brash, loud, confrontative people who love telling the world how successful they are. As a result the scared and hurt child inside that person never gets the nurture and reassurance

that s/he needs and will continue to feel hurt inside, probably becoming louder and brasher as the anger regarding the unmet needs for warmth continues to increase.

6. So what can we do if we have grown up with either inadequate nurture or our own special collection of cruel and hurtful names that we continue to call ourselves? We can learn to tell the truth to ourselves about ourselves and other people in a radical and responsible way.

We can start to take responsibility for our own feelings, which means doing less blaming. We can learn to communicate our feelings effectively, honestly and respectfully. We can learn to ask for the honesty, warmth and support that we all need. Like learning to drive, these skills need to be patiently developed over time. Support will probably be necessary through books, group workshops or individual explorations with a trained professional.

7. May you find the strength, courage and persistence to nurture your self-esteem. It is a task which is demanding and which will bring out the very best and most lovable parts of you. With self-respect comes a new integrity, better psychosomatic health, satisfaction about the self and effectiveness in relationships, based on courage, clarity, honesty and love.

Phiroze Neemuchwala

Your Letters If you would like to write something for the next issue of **info**, please send it to us. You may wish to write about your experience of living with Kallmann's syndrome or contact fellow sufferers. As you are a HYPOHH member, this is your newsletter too, so let's get writing...



About HYPOHH HYPOHH is now in its fourth year and membership is increasing all the time. We now have 80 members all around the world. Most of our members are men, but in recent months, our female membership has been growing rapidly, largely thanks to the Internet.

As you can well imagine, running HYPOHH takes up an enormous amount of my spare time. That said, I enjoy it a great deal and find it immensely satisfying. However, now that HYPOHH is growing so rapidly, perhaps it is now time to start thinking about a proper structure for the support group. For example, we need volunteers to respond to patients' letters, contact specialists, write articles for our newsletter and at some time in the future, a Treasurer. Although we have a sponsor (Ferring Pharmaceuticals), we

still need to look at other ways of funding HYPOHH via The Pituitary Foundation.

What I would like from you all is your input: what do you want to see HYPOHH doing, what kind of organisation do you want to have (eg. set up local groups) and would you be prepared to help out? Something else to think about is how we could raise public awareness of Kallmann's syndrome and other hypogonadal disorders.

The 2nd Open Day in late July could be an ideal forum to discuss the structure and exchange a few ideas. In the meantime, please write, call or e-mail me with your comments, suggestions, ideas, etc...

The next issue of *info* is due to be published in August. 'Hooray!' I hear you cry.

Mark Saunders

Contacting HYPOHH

You can contact us in one of three ways:

Pen & Paper ('snail-mail'):

Mark Saunders
HYPOHH
19 Beresford Court
Park Road
East Twickenham
Middlesex TW1 2PU

E-mail:

HYPOHH@aol.com

Telephone:

(0181) 892 0547

HYPOHH is a patient support group run by volunteers. We rely considerably on the generosity of individual donations and would like to thank those who have sent us a contribution.

If you wish to make a donation, please do not send it to HYPOHH but to:

The Pituitary Foundation
Rachel Smith, Administrator
PO Box 1944
Bristol
BS99 2UB

Tel / Fax : 0117 923 8070

Thank you !

Coming Soon... Following the success of last year's Open Day, HYPOHH is organising a second event for Saturday 25th July. As before, it will be held at the Royal Free Hospital, Hampstead Heath in London.

Although the plans have yet to be finalised, the first half of the Open Day will include three short presentations by leading specialists in their fields. Then the conference will be divided into three working (discussion) groups. The working groups will be of approximately 45 minutes duration each and will rotate, meaning that everybody gets the chance to attend each one of the working groups if they wish to.

If you would like to come along, please fill in the form below, return it to HYPOHH together with a large stamped addressed envelope and we will send you a detailed information pack.

The Open Day is officially due to start at 1 pm, but feel free to come a little earlier if you want. We will be there from noon onwards. See you there !

Provisional Open Day Programme

1.00 - 1.30 Registration and Coffee
1.30 - 1.40 Welcome

Presentations

1.40 - 2.00 Osteoporosis and its Management
2.00 - 2.20 Psychological Aspects of Pubertal Delay
2.20 - 2.40 Specialised Fertility Treatment for Sufferers of Hypogonadotrophic Hypogonadism
2.40 - 3.00 Tea, Coffee & Biscuits

Working Groups (rotating)

Discussion of: Osteoporosis
Psychological Aspects
Fertility Treatment

3.00 - 3.45 1st Session
3.45 - 4.30 2nd Session
4.30 - 5.15 3rd Session



Invitation to the 2nd HYPOHH Open Day



Yes, I would like to come along to the 2nd HYPOHH Open Day on Saturday 25th July. Please send me an information pack.

Name :

Send to:

Mark Saunders
HYPOHH
19 Beresford Court
Park Road
East Twickenham
Middlesex TW1 2PU

Address :

Telephone :

Please enclose a stamped self-addressed envelope

