

# HUMAN GROWTH FOUNDATION

## fourth friday



### From the President's Desk

WINTER 2005

A happy and a healthy 2005 to everyone. 2004 has passed into history. In retrospect, during this past year, HGF has been able to pursue its goals through our PBS Special, the small grants program, our annual conference and the FENS meeting in Florida. Our ability to educate the public on many growth issues is reflected by the fulfillment totals at the National Office. Fulfillments are requests for literature and information received via phone calls and email. 2004 saw an average of 75 requests per month for a cumulative total of over 800 packets of literature dispensed to individuals and families for the year.

I am very excited and optimistic for 2005, a year which marks our 40th Anniversary. Thanks to donations from individuals, private foundations and pharmaceutical companies, HGF continues to reach out to the thousands of families and adults who contact us for support and information. Matching gifts programs are available through many companies. American Express allows card holders the opportunity to make donations through the AMEX Donation site ([www.americanexpress.com/give](http://www.americanexpress.com/give)).

Our membership is growing and reflects a diversity of issues for both children and adults. Growth hormone and growth hormone deficiency are still the main priorities of our members. The complexities of their physical situations are the spark which makes us even more determined to expand our activities and to pursue new booklets in re-

sponse to the issues confronting our family and the general public. The National Office is a major source of support and education. Our internet support lists play a key role in these very same areas. The positive feedback from the persons we contact and assist in various ways validates HGF's mission statement and our efforts to expand our services. Our Annual Conference allows us to reach out to everyone with the latest and most vital clinical information on advancements in the area of growth. The Annual Conference for 2005 is scheduled for April 1<sup>st</sup> and April 2<sup>nd</sup> at Safety Harbor Resort and Spa in Safety Harbor, Florida. I urge all who can attend to make the effort to be there. The program covers a myriad of issues that will be of value and interest. It is being sponsored by HGF in cooperation with Serono Symposia International, Inc. Friday April 1<sup>st</sup> is for registration from 5-7 PM and a cocktail reception at 7 PM. Saturday, April 2<sup>nd</sup>, will be divided into five educational seminars of one hour each in length. The 9 AM seminar is on the topic "Explanation and Description of Depleted Hormone Production Due to Head Trauma" by Dr. Randall Urban. At 10 AM, the topic is "The Examination of the Psychosocial Issues that Confront Abnormally Short Children" by Eric Storch, Ph.D. After a fifteen minute recess, Dr. Dorothy Schulman will discuss the "Description and Explanation of

How Growth Hormone Helps the Small for Gestational Age Child". At this point, everyone is invited to a luncheon from 12:15-1:30 PM. Our agenda resumes at 1:30 PM with a presentation by Dr. Christy Cugini of "Recognizing Signs of Adult Growth Hormone Deficiency and Understanding the Treatment Benefits". The final seminar is conducted by Dr. Marsha Davenport on the "Values of Growth Hormone in those with Turner Syndrome". There will be many opportunities for questions and interaction with the speakers.

There will be a panel in the afternoon geared to the older children attending this event. We will be announcing the winners and three prizes (1<sup>st</sup>, 2<sup>nd</sup> & 3<sup>rd</sup> place) for the children's art contest at this time.

Based on the topics involved, there is no doubt that this Conference's agenda will be of great value to the public and to persons in the medical field. Attendees will be the recipients of a broad spectrum of cutting edge information in the areas of growth and growth hormone therapy. Try to make time in your schedule to participate this year.

Wishing all a prosperous New Year  
I am, sincerely,

Stephen Kemp, M.D., Ph.D.  
President HGF

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**C**an a bump on the head cause growth hormone deficiency?

Absolutely! In fact, head trauma, both severe and minor, is an often overlooked cause of under activity of pituitary gland function, including growth hormone deficiency. Not infrequently, hypopituitarism develops after a head injury despite the lack of skull fracture or loss of consciousness, and many patients sustained head trauma that did not require hospitalization. Children and adults are both effected. However, the majority of cases involve young men in the third decade of life, who have been in a road accident. Pituitary head trauma hypopituitarism occurs within one year of injury in 75% of cases, while 15% of patients are diagnosed five or more years after the trauma. Some reports describe patients whose symptoms developed 30 or 40 years after an accident! Falls, child abuse, and work and sports related injuries have also been described. Interestingly, the chronic neurobehavioral and quality of life problems that many patients with head injury experience closely resemble the symptoms of adult onset hypopituitarism, including growth hormone deficiency. Thus, fatigue, dizziness, depression, anxiety and memory impairment due to deficits of cortisol, thyroxine and growth hormone may be missed because doctors fail to ask about prior head trauma, and patients forget to report even a serious accident that happened many years ago.

The growth hormone producing cells (somatotrophs) are located in the lateral areas of the pituitary gland and are primarily supplied by the hypophyseal arteries and

drained by the long portal veins. These vessels can be directly injured or compressed by swelling of the brain and the pituitary, leading to necrosis of the pituitary cells. Of the various pituitary cell types, the gonadotrophs, that control menstruation, fertility and sexual function, appear to be the most fragile following head injury. Deficiency of the "water retaining" hormone, arginine vasopressin, that is released from the posterior pituitary gland, is also common. In several reports, growth hormone deficiency is discovered in about 15-25% of posttraumatic hypopituitary patients. Reduced levels of thyroid hormone and increased levels of prolactin may also occur. In a few instances, patients actually recovered from documented hypopituitarism caused by head trauma. Presumably, injured blood vessels can regenerate over time and migrate back into the remaining uninjured parts of the pituitary gland. In one young man, full recovery occurred spontaneously after 12 years, while a 32 year old man recovered partially from the effects of a posttraumatic pituitary retention cyst.

If you would like to learn more about this subject, please plan to attend this year's Annual Conference of the Human Growth Foundation, where Dr. Randall Urban, an adult endocrinologist who has extensively studied brain trauma and hypopituitarism, will discuss this often under recognized problem in greater detail!

*Frank Diamond, Jr., M.D.*  
Vice President HGF

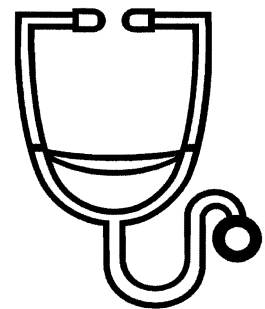
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## ON THE HGF INTERNET SUPPORT LISTS

### Nuances of the ISS and GHD Diagnoses

Idiopathic Short Stature (ISS) is a collective term for short stature of various unknown etiologies. ISS does not include pituitary or classic or idiopathic growth hormone deficiency (GHD). On July 25, 2003, the Federal Food and Drug Administration (FDA) approved a new drug application by Eli Lilly and Company for the use of recombinant (biosynthetic) growth hormone (rGH) for the "indication" of ISS.<sup>1</sup> In summary, the criteria for the ISS indication is: (1) height of more than -2.25 standard deviations below the mean for age and sex, (2) no reasonably identifiable cause of short stature, including growth hormone deficiency, (3) predicted final height of less than 5'3" for males or 4'11" for females.

rGH is approved by the FDA for certain other indications that do not necessarily involve GHD, such as Intrauterine Growth Retardation (IUGR), Small-for-Gestational Age (SGA), Prader-Willi syndrome (PWS), Turner syndrome, and Renal Insufficiency. For those indications for rGH, children with those conditions would fit the ISS indication. The implicit rationale for those indications for the use of rGH is underlying etiologies (causes or origins of diseases and disorders) for ISS.

Underlying etiologies for ISS are not exclusive to those conditions, but also include genetic, molecular, and endocrinological defects<sup>2</sup> familial short stature,<sup>3</sup> biologically inactive growth hormone,<sup>4</sup> growth hormone neurosecretory dysfunction (GHND)<sup>5</sup> and hypothalamic defects

that prevent sending to or receiving by, a properly functioning pituitary of neuroendocrine messages or signals. Frequently, a lack of production by the hypothalamus, or receipt by the pituitary, of growth hormone releasing hormone (GHRH) is the "culprit"<sup>6</sup> for ISS. However, the failure to produce or transmit neuroendocrine substances to the pituitary has many different causes which are often too technically complex, expensive, or time-consuming to evaluate and diagnose. The more practical approach is to prescribe a trial of rGH for a period of six months to determine whether the rGH significantly increases growth and development.

GHND and hypothalamic defects that result in the incapacity of the pituitary to produce rGH are also forms of secondary idiopathic GHD, which have many different labels, but cause the same ultimate physiological effect: the body does not produce any or adequate GH, regardless of the etiology. Significantly, in instances of GHND, a growth hormone stimulation test (GHST), which uses an exogenous provoking agent (e.g. insulin, arginine, l-dopa, clonidine) to stimulate the pituitary always has a "passing" result because the GHST measures only the capacity of the pituitary to produce GH when it receives the message to do so.<sup>7</sup>

Thus a person could produce 20ng/mL of GH with a GHST, and still not produce sufficient GH to promote growth in children; or, to have adequate GH to help promote protein synthesis, bone mass density, and long volume and respiratory strength; and, to help to prevent lipid imbalance and atherosclerosis in adults.

Although the ISS indication substan-

tially broadens the availability of rGH for children who are exceedingly short, it does not cover children who are not unusually short in absolute terms; but are short for familial height, and have (1) dramatic and consistent decreasing growth velocity for a period of six months to a year; (2) low insulin-like growth factor-1; (3) a "passing" GHST; and (4) no identifiable cause for this "spiraling down" of growth velocity.

Consider, for example, a 7 year-old child in the 18th percentile for age-to-height, who in the course of a year, steadily decreased to the 9th percentile for age-to-height, with approximately one inch of growth. The child's IGF-1 level also decreased proportionately during that period to the point where it was close to or below the low normal value or reference range. But, the child "passed" the GHST. Likewise, adults may have similarly low IGF-1 values, but "pass the GHST". In those instances, many ped endos and nearly all adult endos decline to consider the person as being GHD, and decline to prescribe rGH under the diagnosis of GHD.

The results of the GHST usually correlate reasonably well with GHD. However, according to one study involving ISS children, the current GHST cut-off point of 10ng/mL should not be used as the primary criterion for rGH therapy because it does not adequately predict the change in growth that can be expected from rGH.<sup>8</sup> Likewise, another study suggests that while the individual capacity of IGF-1 generation after high-dose GH treatment (6.0 IU/m<sup>2</sup>) determines the growth response on high-dose GH treatment, it does not seem to play a role in growth prediction of children with

ISS.<sup>9</sup> Although a “failing” GHST can be useful in establishing pituitary or classic GHD, it does not rule out idiopathic secondary forms of GHD.

In the latter instances, some ped endos and fewer adult endos order a 12-hr overnight spontaneous growth hormone test (SGHT) for a more definitive diagnosis.<sup>10</sup> The SGHT measures the actual production of rGH over a 12-hr period of time, whereas the GHST measures only the capacity of the pituitary to produce GH. Because it is complex to set up and conduct, expensive, time consuming, and not routine, it may be more frequently used in the investigational and experimental setting of research. Based on those characteristics, the SGHT has been mischaracterized by many medical insurance companies as being “investigational” or “experimental” for the purpose of denying coverage for rGH.

Whether or not a child has short stature, based on an underlying etiology, is important to know for purposes of estimating in gross terms how much the child may grow; but, that knowledge may be known only upon completion of rGH therapy. According to the principal study supporting the ISS indication, without having an underlying etiology for short stature, a child may grow only 1.5 inches more than they would without taking rGH. If a child has an underlying etiology for short stature, the child may grow at a rate as if he/she was diagnosed with GHD, which may in fact be the reality in terms of the child’s natural GH production.

“The diagnoses of ISS or GHD also have ramifications for insurance coverage for rGH. Some insurance carriers exclude coverage or do not pay for rGH under the ISS indication

other insurance carriers are more likely to decline to provide coverage for the diagnosis of ISS because it is not perceived as being medically necessary in all cases, may not result in substantial linear growth in all cases, and is expensive. Nevertheless, it does appear that the ISS indication for rGH is growing and becoming more acceptable to the insurance carriers as they learn of its use to cover underlying etiologies of short stature.”

Earl Gershenow  
Webmaster HGF

#### Endnotes

<sup>1</sup>Talk Paper, T0-56, July 25, 2003  
[www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html](http://www.fda.gov/bbs/topics/ANSWERS/2003/ANS01242.html).

In the first study, children ages 9-15 years taking Humatrope three times weekly until adult height was reached (a mean treatment duration of 4.4 years), exceeded similar children taking a placebo patients by approximately 1.5”. In the second study, children took Humatrope in increasing doses of Humatrope six times weekly until adult height was reached (a mean treatment duration of 6.5 years). “Final height exceeded that predicted at the time of enrollment in the majority of patients, and up to nearly four inches in some. In the high dose group, mean final height exceeded mean height predicted at baseline by nearly three inches.” (See endnote 11)

In approving the ISS indication, the FDA stated: “Short stature has been defined by the American Association of Clinical Endocrinologists and the Growth Hormone Research Society as height more than 2 standard deviations (SD) below the mean for age and sex. This corresponds to the shortest 2.3 percent of children. This new indication restricts therapy to children who are even shorter, specifically more than 2.25 SD below the mean for age and sex, or the shortest 1.2% of

children. For example, for 10-year old boys and girls, this would correspond to heights of less than 4’1”. This would further correspond to heights of less than 5’3” and 4’11” in adult men and women respectively.”

<sup>2</sup>**The GH-IGF-I axis in children with idiopathic short stature.** Blair JC, Savage MO. *Trends Endocrinol Metab.* 2002 Oct;13(8):325-30. Section of Paediatric Endocrinology, Dept of Endocrinology, St Bartholomew's and the Royal London School of Medicine and Dentistry, London, UK EC1A 7BE. **Genetic defects in the control of growth hormone secretion.** Gertner JM, Wajnrajch MP, Leibel RL. *Horm Res.* 1998;49 Suppl 1:9-14. Department of Pediatrics, Cornell University Medical College, New York, NY, USA. **Growth hormone neurosecretory dysfunction associated with ring chromosome 18.** Aritaki S, Takagi, Someya H, Jun L. *Acta Paediatr Jpn.* 1996 Oct;38(5):544-8. Department of Pediatrics, Tokyo Medical College, Kasumigaura Hospital, Ibaragiken, Japan. **Growth disorders in Down's syndrome: [growth hormone treatment].** Pallotti S, Giuliano S, Giambi C. *Mi-nerva Endocrinol.* 2002 Jun;27(2):59-64. [Article in Italian] Dipartimento di Fisiopatologia Medica, Università degli Studi di Roma La Sapienza, Rome, Italy.

<sup>3</sup>**Short children with familial short stature show enhancement of somatotroph secretion but normal IGF-I levels.** Bellone S, Corneli G, Bellone J, Baffoni C, Rovere S, de Sanctis C, Bona G, Ghigo E, Aimaretti G. *J Endocrinol Invest.* 2002 May;25(5):426-30. Department of Medical Sciences, University of Piemonte Orientale, Novara, Italy. **Extensive phenotypic analysis of a family with growth hormone (GH) deficiency caused by a mutation in the GH-releasing hormone receptor gene.** Netchine I, Talon P, Dastot F, Vitaux F, Goossens M, Amselem S. *J Clin Endocrinol Metab.* 1998 Feb;83(2):432-6.

<sup>4</sup>**Biochemical markers of growth**

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**<sup>5</sup>Growth hormone neurosecretory dysfunction.** Bercu BB, Diamond FB Jr. *Clin Endocrinol Metab*. 1986 Aug;15(3):537-90. **Growth hormone neurosecretory dysfunction: A treatable cause of short stature.** Spiliotis BE, August GP, Hung W, Sonis W, Mendelson W, Bercu BB. *JAMA*. 1984 May 4;251(17):2223-30. **Reduction of the pituitary GH releasable pool in short children with GH neurosecretory dysfunction.** Aimaretti G, Bellone S, Bellone J, Chiabotto P, Baffoni C, Corneli G, Origlia C, de Sanctis C, Camanni F, Ghigo E. *Clin Endocrinol (Oxf)*. 2000 Mar;52(3):287-93. Division of Endocrinology, Department of Internal Medicine, University of Turin, Italy; Division of Paediatric Endocrinology, Regina Margherita Hospital, Turin, Italy.

**<sup>6</sup>Growth hormone releasing hormone receptor.** Gaylinn BD. *Receptors Channels*. 2002;8(3-4):155-62. Division of Endocrinology and Metabolism, Department of Medicine, University of Virginia Health System, Box 801411, Charlottesville, VA 801411, USA. [bg2g@virginia.edu](mailto:bg2g@virginia.edu) **Extensive phenotypic analysis of a family with growth hormone (GH) deficiency caused by a mutation in the GH-releasing**

**hormone receptor gene.**

**<sup>7</sup>Growth hormone (GH) provocative testing frequently does not reflect endogenous GH secretion.** Bercu BB, Shulman D, Root AW, Spiliotis BE. *J Clin Endocrinol Metab*. 1986 Sep;63(3):709-16.

**<sup>8</sup>Near adult heights after growth hormone treatment in patients with idiopathic short stature or idiopathic growth hormone deficiency.** Frindik JP, Kemp SF, Hunold JJ. *J Pediatr Endocrinol Metab*. 2003 May;16 Suppl 3:607-12. University of Arkansas for Medical Sciences, Little Rock, AR, USA. [frindik-paul@uams.edu](mailto:frindik-paul@uams.edu)

**<sup>9</sup>Recombinant growth hormone for idiopathic short stature in children and adolescents.** Bryant J, Cave C, Milne R. *Cochrane Database Syst Rev*. 2003;(4):CD004440. Wessex Institute for Health Research and Development, University of Southampton, Mailpoint 728, Biomedical Sciences Building, Bassett Crescent East, Southampton, Hants, UK, SO16 7PX; **Reproducibility in patterns of IGF generation with special reference to idiopathic short stature.** Selva KA, Buckway CK, Sexton G, Pratt KL, Tjoeng E, Guevara-Aguirre J, Rosenfeld RG. *Horm Res*. 2003;60(5):237-46. Department of Pediatrics, Oregon Health & Sciences University, Portland, Ore. 97239, USA. [kselva@lhs.org](mailto:kselva@lhs.org)

**<sup>10</sup>Diagnostic validity of 12-hour integrated concentration of growth hormone.** Richards GE, Cavallo A, Meyer WJ 3rd. *Am J Dis Child*. 1987 May;141(5):553-5.

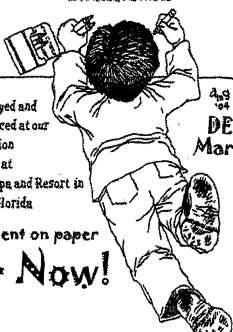
**<sup>11</sup>Effect of growth hormone treatment on adult height in peripubertal children with idiopathic short stature: a randomized, double-blind, placebo-controlled trial.** Leschek EW, Rose SR, Yanovski JA, Troendle JF, Quigley CA, Chipman JJ, Crowe BJ, Ross JL, Cassorla FG, Blum WF, Cutler GB Jr, Baron J; National

Development-Eli Lilly & Co. Growth Hormone Collaborative Group. *J Clin Endocrinol Metab*. 2004 Jul;89(7):3140-8. Comment in: *J Clin Endocrinol Metab*. 2004 Jul;89(7):3138-9 PMID: 15240583 Developmental Endocrinology Branch, National Institute of Child Health and Human Development/NIH, Building 10, Room 10N262, 10 Center Drive, MSC 1862, Bethesda, MD 20892-1862, USA.

Enter the Human Growth Foundation's  
**Childrens' Art Contest**

PRIZES: 1st- \$100. 2nd- \$75. 3rd- \$50. Plus Honorable Mentions  
Draw on 8-1/2" x 11" paper with name and age in the lower right corner.  
Full name, address and phone # on back of drawing.

Send to: Human Growth Foundation  
997 Glen Cove Ave., Ste. #5  
Glen Head, N.Y. 11545



Finalists displayed and winners announced at our Annual Convention April 2nd, 2005 at Safety Harbor Spa and Resort in Safety Harbor, Florida

Put your talent on paper  
**Enter Now!**

**DEADLINE\***  
March 1, 2005

## KIDS ART CONTEST

Deadline extended to  
March 15, 2005!!!  
Please check our website for  
more information.  
[www.hgfound.org](http://www.hgfound.org)

## DON'T FORGET! HGF COUNTS ON YOUR

If you have forgotten your membership renewal please contact the National Office at 1-800-451-6434. Your membership will help us to continue to provide our many services to the Human Growth Foundation community.



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**HUMAN GROWTH FOUNDATION  
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**Target Audience** —Families concerned about their child's growth and adults who wish to learn more about growth hormone deficiency. This course is designed for physicians, scientists, advanced practice nurses, fellows and other health professionals interested in or trained in endocrinology, internal and family medicine. The course will be of particular interest to basic and clinical investigators involved in growth hormone research and gerontologists and geriatricians interested in hormonal/growth hormone therapy.

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Room rates are **\$119.00 + \$10.00 resort fee and taxes**. Reservations must be made by **March 2, 2005** to receive this rate. Please mention the **HGF Conference** when making your reservations.

The Safety Harbor Resort is located in the city of Safety Harbor on the northwest side of Tampa Bay. Please call for specific directions.

Please fill out and detach the form provided below for registration for the Annual Conference.

NAME: _____	_____ FAMILY _____ PHYSICIAN _____ NURSE
ADDRESS: _____	How many in attendance: _____
CITY: _____ STATE: _____ ZIP: _____	Attending reception on Friday evening? Y _____ N _____
E-MAIL: _____	Are you an HGF member? Y _____ N _____
PHONE: _____	Would you like to become a member? Y _____ N _____
	Non-member—\$35.00/per person
	If yes, please add \$35.00 to the registration fee listed below to qualify for the member discount.
	<u>Members of HGF:</u> Individual—\$25.00 Children —1/2 price
	Physician—\$80.00 Nurse—\$60.00

**Please send form and registration fee to:**  
Human Growth Foundation  
997 Glen Cove Avenue-Suite #5  
Glen Head, New York 11545

Dear Elizabeth,

I found your e-mail address on the HGF website. Our daughter, Susan (10 years old) has been doing growth hormone therapy for less than a year. She is showing great results, but wants to discontinue.

My wife, Alice and I discussed this and thought that she should be free to make her own decision, but that she might benefit from your insights and perhaps others that you know that have struggled with the treatment from time to time.

Would it be okay for Susan to drop you an e-mail to begin the dialog?

Thanks for your time.  
*John Richards*

Dear John and Alice,

Thank you for your e-mail and yes I would love to talk to Susan. I was 10 when I started growth hormone and I can give her tons of advice. I can talk with her about what to say to her friends, teachers, and about growth hormone shots. I would also call the Human Growth Foundation at 1-800-451-6434 and ask for Patti Costa, she can send some great information that would help.

I am looking forward to hearing from Susan.

Bye,  
*Elizabeth*

Hello!!

My name is Kathy and I am 16 years old. In biology we are doing a research project on genetic disorders, and my group chose Achondroplasia. I don't know if you had this or

not, but nevertheless I hope you can help me. Part of my project is to find out the psychological and emotional aspects of this growth problem. It sounds like there are some challenges one might face. I would love to talk with you more and I hope you can help me.

Thanks,  
*Kathy*

Hi Kathy,

It sounds like a great project you are doing in your biology class. I did not have achondroplasia. I had growth hormone deficiency. I think the best thing for you to do is call the Human Growth Foundation at 1-800-451-6434 and ask if they can send you a booklet about achondroplasia.

Take care,  
*Elizabeth*

Dear Elizabeth:

I just wanted to thank you for the phone number. They are sending me a booklet, and they also gave me the number for Little People of America. I might have the opportunity to speak with someone who has achondroplasia in my area...so I just wanted to say thank you so much.

Thanks,  
*Kathy*

Hi Elizabeth:

My name is Justine and I have been taking growth hormone shots for about 6 months. But, lately, I have been getting really nervous and freaking out so this month has been kind of rocky for me. I am 12 by the way. I don't know what to do because I get nervous almost every time.

My mom has tried giving me the shots, but it has been causing upsets in my family and my mom and I are getting frustrated. I don't want to stop the medication because I have been doing very well. But, this month I have been so nervous about it hurting. I do it in my leg and my mom does it somewhere else. I have been so nervous this month that I am afraid that everything is going to go wrong. My mom and I have tried everything. Do you have any suggestions?

Thanks,  
*Justine*

Hi Justine:

I wonder why you are getting nervous about your shots? Have you talked to your doctor or nurse? Have you tried a numbing cream? I used to put an ice cube on my leg or arm before my shot. You might also ask for help from your school nurse. You might also try calling the Human Growth Foundation at 1-800-451-6434. The Foundation is a nonprofit organization that helps people with growth problems and has cool pamphlets and information. I hope this helps. Let me know how you do.

Bye,  
*Elizabeth*

Hi Elizabeth:

My mom and I are trying something new. We both hold the needle and she gives me the shot. The nurse came out to my house to help. I'll keep in touch because it's nice to know someone who went through the same thing.

Bye,  
*Justine*

# fourth friday

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Your tax deductible donations have begun the establishment of The John Hickey Fund . However, the fund is an ongoing project. We ask you to keep the JHF in mind when deciding what charitable contribution you are going to make during 2005, and in the future.

