

# The Even Exchange

Issue 16 - September, 1996

The Newsletter of  
Klinefelter Syndrome  
and Associates of  
Roseville, California.



## SCIENTIFIC ADVISORY COMMITTEE REPORT

The first Klinefelter Syndrome and Associates Scientific Advisory Committee (SAC) met in Seattle on July 26-28, 1996. The SAC meeting, which preceded the Klinefelter Syndrome and Associates national meeting by one day, was attended by the following permanent and temporary members: Ronald S. Swerdloff, M.D., Chairman (Endocrinology, UCLA); Alvin Paulsen, M.D. (Endocrinology, University of Washington); Joe Leigh Simpson, M.D. (Gynecology and Genetics, Baylor University); Alan Rogol, M.D. (Pediatric Endocrinology, University of Virginia); Bruce Miller, M.D. (Neurology, UCLA); Carol Sprouse, Ed.D. (Pediatrics, George Washington University); Geoffrey Wooming, M.D. (Sacramento, CA) and Melissa Aylstock (Klinefelter Syndrome and Associates).

The meeting focused on scientific, medical, and educational issues affecting men and boys with K.S. and other related genetic disorders. Dr. Swerdloff described a previously approved survey to be used to gather descriptive information about individuals with K.S. A pilot form was distributed to K.S. men, boys,

*See SAC, page two . . .*

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## Community Building Through Self-Help Groups

*By Hector Balthazar*

*The following is an excerpt from the keynote speech Mr. Balthazar gave at the Second Annual Kansas Conference on Self-Help Groups on April 27, 1996. Mr. Balthazar, BA, BEd, MSW is the former National Director of the Self-Help Program Canada and the Canadian Council on Social Development.*

It is very difficult to understand the self help movement without looking at its social antecedents. The Industrial Revolution has lasted for approximately 300 years; it has had profound effects on the type of world in which we now live. We cannot deny the enormous benefits it has given us all — great discoveries in science and medicine, an enviable standard of living, advances in education, etc. However, precisely because it prized efficiency and productivity above all else, family and relationships suffered such a severe blow that a vast number of problems were created, both personal and social. To some, traditional institutional and professional ways of responding to certain problems fell short of the mark. Self-help/mutual aid groups came into existence as one response to the consequences of the Industrial Revolution, not only to solve personal problems but to recover the humanity that was lost through decades of depersonalization.

### The Magic of Self-Help Groups

Today, about a million people are involved in self-help/mutual aid groups in Canada and many more millions participate in self-help groups in the United States. It is an approach that appeals to many people and is not only a method that complements traditional forms of help but also can serve as an alternative form of help. It is different and, for many people, extremely effective.

Generally speaking, groups are open, welcoming to all who share the same problem, easy and non-threatening. There is an underlying expectation that members attend groups to get help, to give help, and to help themselves. Knitted into this is the motto retained from the Integrity Groups, "you alone can do it, but you can't do it alone."

*See SELF-HELP, page three . . .*



The **Even Exchange**

September, 1996

A Publication for Support Group News by Klinefelter Syndrome and Associates of Roseville, California

Executive Director  
Melissa Aylstock

K. S. and Associates is an educational, non-profit organization dedicated to increasing public awareness of Klinefelter Syndrome (and other male sex chromosome variations) and providing support and information to those dealing with the syndrome.

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Visit our World Wide Web site at:  
<http://www.medhelp.org/web/ks.htm>

or Email us at:  
[ks47xxy@ix.netcom.com](mailto:ks47xxy@ix.netcom.com)

**From Melissa . . .**

Once again we meet in order to "exchange" ideas and information. Maybe some of you newcomers have wondered where we got the name *The Even Exchange*. It came about because we are trying to provide a medium where we could exchange information about Klinefelter Syndrome. We wanted the information to be an "even" blend of professional opinion and anecdotal information. Sometimes medical professionals and families become polarized by their individual experiences with Klinefelter Syndrome. We wanted to be able to bridge the gap with our newsletter. We hope that we provide a valuable resource to both families and professionals alike.

Most of you know we had our '96 conference in the Seattle area in July. Overall, it was very successful with some really terrific speakers, but the best, best, best part was meeting all the families. That alone makes these conferences worth all it takes to get there.

We had some families who made monumental sacrifices to come, yet even these families report that it was one of the greatest treks of their lives. It wasn't because of the program, excellent though it was. It was because they got to touch and listen and be with other families who understood what being a KS family/individual is all about.

Our 1997 K.S. conference is scheduled for July 25-27. It will be at the North Shore Hilton, (708) 679-7000, in Skokie, Illinois. The hotel is approximately twelve miles from Chicago's O'Hare International Airport. More information will be available in the January issue.

Thank you all for your patience with the newsletters. Our organization continues to grow weekly yet Roger and I have not been able to lobby for more hours in the day. Your understanding in the matter of timing is so appreciated.  
Hugs,

**SAC, from page one**

and their parents (of children) before distribution to approximately 2,000 K.S. individuals later this year.

It was agreed that the SAC would serve, at the discretion of the Klinefelter Syndrome and Associates Board of Directors, as a reviewing body for requests to use the K.S. membership lists for identification of potential research volunteers for clinical investigations. If approved by the Board of Directors of Klinefelter Syndrome and Associates, a request form will be developed as a template for investigators to use to describe projects for which they would need anonymous information from the Klinefelter Syndrome and Associates computer files or to use if they wish to utilize Klinefelter Syndrome and Associates member lists to send description of research projects needing volunteer subjects. All projects must be approved by the SAC review group and the investigator's Institutional Review Board.

The SAC agreed to the need to develop improved educational materials about K.S. for distribution to individuals, parents, or interested parties of those with K.S. Additional materials will be developed for education of physicians, educators, and behaviorists likely to have contact with individuals with K.S.

The SAC discussed plans to develop a Regional Consultant Network to provide names of individual physicians and medical centers where K.S. men and boys could be referred. The concept of Regional Specialized Centers of Excellence was discussed. Such centers would provide comprehensive consultative care including psychological, educational, endocrinological and neurological advice.

SAC felt it could be a nucleus for development of a prioritized list of focus areas on K.S. to stimulate new clinical and basic investigations on sex chromosome aneuploidy (extra or missing X or Y Chromosome) and its clinical manifestations. In a parallel fashion SAC could

See SAC, page seven . . .



**Self-Help, from page one**

Because groups are free, informal and non-judgmental, members may be satisfied to simply get valuable information on their problem, and tips on how to cope with, or resolve it. They may not wish to stay on for a deeper understanding and experience of the self-help/mutual way. Those who hunger for more than problem resolution may find, although this is not fool proof, an entirely new perspective on life as they delve into the "giving of help" part of the process. A particularly astute member graduate of this process called it the "birthing of compassion" — a necessary ingredient for bonding with others.

**"you alone can do it, but you can't do it alone"**

Bonding is made possible because the shared problem invites trust among members. Trust is necessary for the surrender of members to the group process. We maintain defenses because we are afraid of change, of taking the risk. This is what is ironic about suffering. Everyone must face suffering and any action on our part to avert it only causes more suffering. Working through these adversities without using any means of escape has very beneficial effects on one's mental health. Precisely because all have the same problem, members of self-help groups are quick to know when a member is trying to avoid change or justify unproductive behavior. They are quick to get him/her back on track. A person who had long suffered as a victim of incest and who had kept it a deep, dark secret within herself until she was able to surrender, said it was like an "emotional jacuzzi." If you try to cheat nature by circumventing the demands life makes on you, you will suffer many times over and gain nothing. The serenity prayer says it all — courage to change, the serenity to accept what one cannot change and wisdom to know the difference. That means no cheating, no lying, no avoidance, no escape, no excuses.

There is magic when defenses come down, locked up energies are released and this happens with others going through the same process. It gives credence to the saying that "the healing is in the wound." People are changed. You will know them by their detachment to trivia and by a quality of connection to others and all living things in nature. They become wonderful people; the salt of the earth.

I better understood the depth and quality of change the self-help/mutual aid experience can effect two weeks before my youngest daughter was to marry. I was painting parts of the outside of my home when the father of the lady next door who was on holiday came to me and offered his help. I couldn't believe my ears that someone who was on holiday and who didn't know me would do such a thing. Naturally, I refused but he insisted. He worked with me all week. In the course of our many conversations, he shared that he had been an alcoholic some twenty-five years earlier and his AA experience had kept him sober and he had discovered how much helping others helped him. His style had shifted from an egocentric to an altruistic mode. More than that, he connected not only to people but to animals and nature in general. His questions about birds and trees and plants that his eyes could not clearly perceive gave indication of that.

We must not overlook other potential forms of transformation that are part of the self-help group process and that have their place even though they may not effect as major shift in one's perspective on life. For example, there is the role that example plays. Example has a central place in self-help groups. There is always someone who has gone further, who has done more and now inspires.

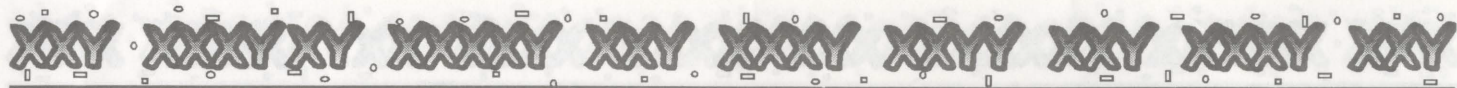
Such was Lindy Fraser from Ottawa who founded the first self-help group for osteoporosis at age 87. This woman suffered from that condition from the time she was in her twenties, even before it was properly identified. Most of her life was spent as a guinea pig subject for whatever researcher or medical doctor who wanted to study her condition. After she experienced positive change in herself as a result of exercise, diet and medication, she felt the urge to share this with others suffering from the same plight. She worked tirelessly at her typewriter, fifteen hours a day until she died at 96. By then she had been responsible for initiating groups in North America, Australia, New Zealand and Europe.

And then there was Lucien Landry. This man lived his life from birth in an orphanage. These were the days before deinstitutionalization and as it happened management of the orphanage also ran the mental asylum next door. By age 12, Lucien exhibited behavior staff found difficult to control, so they transferred him to the asylum. He was there two years and escaped, jumping over the wall. He lay low for two years for fear of being found out. He slept in basements of apartments and worked at odd jobs which allowed him to keep body and soul together. Then he got bold and helped others to jump over the wall. They formed a self-help group to help each other survive in the outside world. The group continues its work to this day. Lucien is now a board member of both a mental hospital and the board of the Quebec Mental Health Association. He is also the ombudsman for the mentally ill in the very hospital from which he escaped. Talk about empowerment!

These two stand as exceptional people and not many self-help groups can claim to have such individuals as models. But the principle of one being an example to others in the group is very active as is the principle of practicality. Self-help groups are known to be supremely practical.

See SELF-HELP, page five . . .

**Example has a central place in self-help groups. There is always someone who has gone further, who has done more and now inspires.**



## Seattle Conference Report

By Carol

Six weeks after we had learned our 15 year old son Doug was a 47,XXY/46,XY mosaic, I was fortunate enough to attend the third annual Klinefelter Syndrome and Associates conference in Seattle, Wash on July 26-28, 1996. What can I say about something that finally validated all the maternal instincts that had been ignored or casually dismissed for so many years? What a relief to know that I was not so out of touch with my own son all those years, when I kept trying to explain the developmental milestones that were not technically delayed, but were still late, or the frustration outbursts and other unusual behaviors that were out of character! It was like discovering a compass on a long voyage through uncharted territory.

The Friday night support group meeting with other parents of adolescent boys was unreal. We all thought our sons were the only ones who collected all the minutiae in the world (tear out cards in magazines, etc.), cooked up late night concoctions while everyone else slept (and of course left the mess for mom to clean!), told amazingly witty and funny stories, and did countless other things.

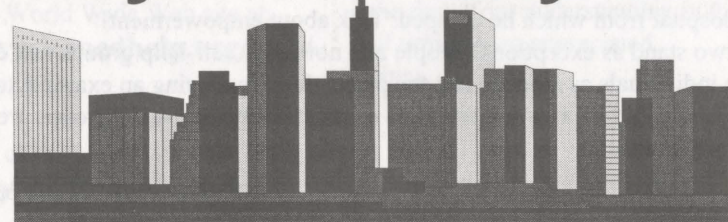
The one thing that struck me the strongest was the loving tenderness and helpfulness these guys openly displayed to their families. I smiled as I watched young Greg [redacted] firmly, but gently guide his mother through a crowd and up to her room to rest a moment or so before that night's meeting. It was a sight to see several adolescents troop into our meeting when theirs was dismissed, and each would head to mom, put an arm or two around her shoulders, inform her he was going to play basketball with the guys, give a big, irresistible grin with a boyish air of enthusiasm and head out.

I can't describe the bond that took place in those two days. It was like a reunion with dear and familiar friends. It was a safe place to laugh, cry and yes, even be angry and frustrated. Some may have thought the parents were too uptight or angry, but I feel it is important to remember that at such a gathering, folks are at different levels in their dealing with the diagnosis. Some were still angry and some were still grieving and some had moved on to acceptance, but it was important to me that each one's feelings be respected and each one feel safe enough to express his or her fears, anger, joys, and sorrows.

The Friday morning clinic was a real treat, because the doctors treated each of us as a valued client worth listening to. The strides being made in research and treatment of Klinefelter Syndrome may seem to be baby steps to those of us living with the anomaly, but at least someone is moving and advancing our cause in the medical world. I have to applaud the efforts of Dr. Swerdloff, Dr. Paulsen, Dr. Plymate and others. Their compassion and astuteness were profound. The announcement of the addition of a Scientific Advisory Committee to Klinefelter Syndrome and Associates is a giant leap forward for our organization and our families.

Start now! Make plans to attend Chicago next year. It is worth whatever sacrifice or effort you will make. No monetary value could ever be put on an experience of a lifetime.

## Chicago '97 July 25-27



By Doug

I met a lot of new friends at the conference in Seattle, Wash. I met boys who were even taller than I am, and that was pretty good. I also met boys and men who are a lot like me, and that made having K.S. not so scary or lonely. I had only found out about my extra X chromosome six weeks before the conference. I didn't want to go at first because I had gone to so many different things that did not help me. It was hard to believe this one would be any different.

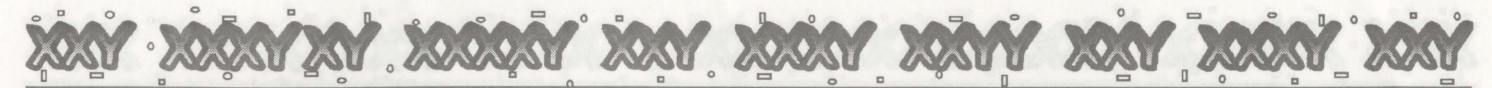
At the Friday night support group meeting for teenage boys, we all found out all the different things we had in common. I learned that the angry feeling I get inside sometime that I just can't make go away no matter how hard I try is because my testosterone is dropping too low, and my body is not working right.

Before the conference, I did not want to take the Hormone Replacement Therapy because I had tried too many things that did not work. After the conference, I could not wait to go home and tell my doctor I wanted to start with the testosterone. I also liked it because the doctors at the clinic talked to me like a regular guy and not like I was retarded or stupid or something.

I am not a bad boy or a freak. I am an eXtra special boy with an extra X chromosome on many of my cells. I am a regular teenage guy who likes cars and girls and having fun. I can do or be anything I choose. I want to help other boys like me to know that they do not have to stay trapped inside of themselves and be afraid to come out. The world is not such a bad place to live in after all. I have lived locked inside myself for many years, and I am living outside of myself now. I like it on the outside better.

*Editor's Postscript: Doug is fifteen years old. He wrote this soon after returning home from the July '96 conference. After being seen by his health care plan, the doctors told Doug and his*

*See DOUG, page seven . . .*



## Self-Help, from page three

It was my fortune to discover a group of agoraphobics when I was looking for groups to feature in a documentary film on self-help/mutual aid groups. I was only allowed in the group as an observer, sitting at the back of the room, having promised to say nothing to anyone except at coffee breaks. One night a lady came in all out of breath excusing herself for being late and declaring that her car was not working and that she had to come to the group by way of the city bus. I thought nothing more of it until it transpired that no one in the group had been on public transportation for years. The group decided that night to do something about their bus problem. They all got a pass and congregated at the same bus stop for the first hour of their Tuesday night meeting. Everyone boarded the bus. During the ride, anyone who got to a point where he or she could stand it no longer would get off and into one of two cars following the bus. I was driving one of the cars.

In three months everyone had sufficiently conquered their fear of public transportation and moved on to other areas that affected their functioning. Their very success greatly motivated them. They tackled elevators, holding hands and praying God to get to the top. From there they moved to shopping centers, banks and restaurants. That group is now disbanded, having set its goal on a very specific, practical task and once accomplished, never felt the need to continue meeting. This is yet another example of the range of goals and activities the self-help approach offers.

## Hope for Our Future

It is because of the potential for building authentic community, based on people who have experienced the mutual aid phenomenon, that the self-help movement offers such hope for the future. Among others, self-helpers have a real feeling for the world and are acutely aware of the precarious state it is in. Indeed, the world needs awakening to the planet's dangerous condition. Whole species of butterflies, birds and fish have disappeared. The immune system of dolphins and sharks is breaking down, including those of humans, AIDS being one example. The air in such cities as Los Angeles and Bombay is so polluted that their inhabitants have suffered permanent damage. Residents of certain parts of Mexico City breathe in the equivalent of two packs of cigarettes a day, because the air is so polluted. The sun, adored as a god in ancient times and revered as our friend, giver of life, food and energy, is now becoming a foe from which we must shield ourselves. This planet has existed for millions of years and yet in 300 years we have managed to bring it to a state of peril. We have also made great strides toward destroying community and the family. Only remnants remain of authentic community life, in societies that are still primitive or in certain groups animated by religious beliefs. Relationships in mainstream society are close to, if not already, in shatters.

This is why the self-help movement and its potential for building community is so important for the survival of the planet. Political parties and the powers that be are primarily interested in maintaining power and will, therefore, only address matters that preoccupy voters of the day such as money, jobs and standard of living. It is a narrow-minded view that makes short shrift of fundamental issues such as human relationships and the planet's survival. It took a transformed member of a self-help group at a conference on self-help/mutual aid to suggest that we should all pull together and settle for a more modest standard of living, and be ready to share our jobs with our co-workers, instead of seeing them declared redundant and thrown into despair. Now there's the stuff of which authentic community is made.

Often, we give too little thought and appreciation to the role that the self-help experience can give to the birth of community. It is seen as a by-product and because of this it loses its true significance. We have seen how membership in self-help groups can affect people in different ways and at different levels. My personal bias, of course, is to

hope that more and more people will draw from their self-help experience a new life that renders them one not only with all people but with the broader range of all living things on this planet so that we can guarantee its continued existence. When mother earth is sick we are all sick and when she is well we inherit its beneficent effects. It is my firm belief that the self-help movement has a major role to play in turning things around in society. The self-help group approach is one way to be born into the reality that we are all one, that we are connected to everything on this planet and that our behaviors and attitudes reflect a deep respect for all living things. Progress must be viewed within the context of human and environmental betterment. Otherwise, it is not progress, and by human I mean the full range of the human dimension including the physical, emotional, social and spiritual aspects. Our world is not there yet.

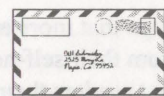
*Reprinted with permission from the May 1996 issue of Helping Hands, a publication of the Self-Help Network of Kansas, Dept. of Psychology, Wichita State University, 1845 Fairmont, Wichita, KS 67260-0034, (800)445-0116.*

## Northeastern Klinefelter Syndrome and Associates Support Group Meeting

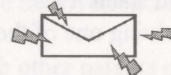
A regional support group meeting will be held on Sunday, November 10, 1996 from 1-5 PM at the Lahey Hitchcock Clinic, Burlington, Mass. A \$10. per family donation would be appreciated to cover costs of the facility. For more information and directions, contact Stefan at [redacted]



# Letters



*(Editors Note: In this issue, we are featuring E-mails from our Klinefelter Support E-mail list. See our May, 1996 issue for a description of this list or visit our World Wide Web page at <http://www.medhelp.org/web/ks.htm>. The E-mail list is quite active with over 60 participants and it generates 20 to 30 E-mails a day. As always, we obtain your permission before including your letters in our Letters column.)*



Date: Tue, 20 Aug 1996 13:45:15 -0500

To: Klinefelter Email List <[redacted]>  
 From: MR EDWARD H [redacted] <[redacted]>  
 Subject: KS&A: Sum Thoughts...

Greetings All,

Personally speaking of course; it appears to me, that I am different. I may compensate and adjust, reading the social and cultural signs like a book, to the general population. However, my imagination and creativity are strong. And quite frankly, I enjoy being in my head. I am best when alone, and left to be...me.

It is evident that I perceive and interpret things differently. Different boundaries exist in my innate scheme. I feel I am soft hearted, and vulnerable for this. Finding the niche to crawl in is impossible, I must create my own. Society (USA) tries to mold us to their thinking, so we may fit. Everything is set up to make us "normal, productive" citizens. Unfortunately...and fortunately, I am different. The cost for this...well, like most things, has bad points and good.

I suppose the worst for me was my decision to study psychology, because I thought I was mentally ill and wanted to understand what was going on. I wasn't diagnosed until I was 16 years old, and didn't receive treatment until the late 20s, and further, wasn't on a constant regime until about four years ago, and just recently on the patch. So my entire childhood and adolescence was a big mountain of mis-conceived lessons. I truly thought that I was "nuts", and needed to grasp a sense of my self by the tail and handle the situation. Further through adult being, I understood my needs, wants and desires were much different then my friends. I turned down a marriage, because I felt I needed to further grow as my self. That constant chase to understand, "who am I?" It just wasn't happening. I'm not a neuro-psychologist, although I find it fascinating, but I think, we think differently. Perhaps our brain chemicals have a specific mix, different then the general population, who knows?

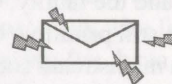
This possibility, however, makes us unique and special. This is the good point: because of this ability to perceive differently, and further communicate this perspective, we may be construed as "genius" or "nut," either way, it is special. Look at all the historical figures we have to look up to, all the social misfits; Einstein, Franklin, Columbus, Luther, etc., deemed by society to be unacceptable, until their genius emerged. Who knows what gifts our population has to offer. Who knows the countless millions before us gone undiagnosed, yet contributed significantly to humanity?

As general as my thoughts are, I believe we are gifted. We are a gift. Sure it is a pain in the butt, but only if one is blind. If one can see, one can learn, and one can make the difference. As the world at large tries (in vain mind you) to mold us to their way of thinking and being, we are forced into our heads. We just don't see it that way!!! But we understand, they don't get it. So we can be frustrated, or we can be empathetic.

While frustrated, I have embarked on moral and ethical advocacy like a pitbull, serving the injustice with full power and authority, a quest, an internal rage projected at the stupidity of bureaucracy. It has cost me dearly, several jobs of human service, because of my impatience. OTOH (Editor's note: This is Net shorthand for "On The Other Hand"), empathy has bestowed riches beyond normal compensation. I'm not talking material, nor financial, but spiritual and humanitarian. When we are empathetic, we possess an ineffable quality of understanding. We have within us the ability to see the big picture all at once, to take it in, absorb it, and deal accordingly. Being frustrated all the time, makes one very patient, a major need for our existence. Heck, an adrenaline rush can overwhelm us and incapacitate. Because of my soft-heartedness, emotions reign. A lot of rage exists because of countless years of frustration, an open wound easily accessed. But if I can choose, the course of productivity and joy, empathy and the way of the heart bring peace and understanding to my soul.

Thanks for listening,  
 ED

Creativity brings Joy!  
 Joy brings Happiness!  
 Happiness brings Health!  
 Health brings Clarity!  
 Clarity brings Understanding!  
 Understanding brings Creativity!  
 - - Ed



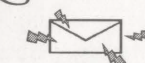
Date: Tue, 16 Jul 1996 13:15:30 -0400  
 To: Klinefelter Email List <[redacted]>  
 From: Arturo  
 Subject: Prices

To all,  
 I am looking at the list of prices of the different methods of administering testo in the USA, in The Medical Letter, a very reputable and independent source of information in therapeutics.

See LETTERS, page seven . . .



# E-Mail Letters Continued



from page six

(E-mail from Arturo continued)

Testoderm™ - one 4mg or 6 mg (scrotal) patch - \$ 71.76/month  
 Androderm™ - two 2.5 mg patches - \$97.50/month

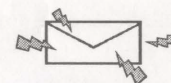
Testosterone cypionate - 200 mg IM every 2 weeks - \$ 3.88/month

Testosterone enanthate - 200 mg IM every 2 weeks - \$ 3.94/month

The scrotal patch requires shaving of the scrotum and may not adhere to the skin — particularly with the decreased size testis of K.S. — but it causes much less skin irritation.

Androderm, the patch that can be used anywhere, unfortunately may cause skin irritation in some persons.

Arturo



Date: Wed, 21 Aug 1996 17:42:30 -0400  
 To: Klinefelter Email List <[redacted]>  
 From: Stefan  
 Subject: Re: [KS&A] Acceptance

Yes Carol, this is completely true for me. I was only able to take risks and make changes after thinking it through for a long period of time. I recently made a change and took a big risk by moving away from family and friends and starting a new job in a new field. It was something I did without a lot of thinking, although I knew it was something I had to do, because I would have let a lot of people down. I have always been frightened to try new things and this hasn't been easy. I've been in this new place (Boston, MA) for six weeks now and am dealing with a lot of depression. I do feel a certain pressure

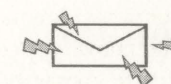
to succeed and I know in my own mind I will. I've always succeeded when others told me I couldn't or wouldn't.

I know I'm getting way off of the subject here, but I have to mention this anyway.

I was told somewhere around 7th grade by a therapist before K.S. was ever diagnosed that I would never amount to anything, I would never graduate high school and I would probably live with my parents forever. I had a lot of learning, language and speech problems throughout my life and had constant tutoring. They said I would never graduate from high school, I did, barely. I decided after high school to ditch tutoring, because I was sick of it and would get by on my own. I began at community college after HS, graduated in three years, part time with an A.S. in Business Administration, no tutoring, no special classes — that was the way I wanted it to be, no special attention. I transferred from there to a small liberal arts school in New England and went on to complete two B.S. degrees in three years. I never had any tutoring or any special help, because I didn't want to be a "special student." I graduated with honors and accomplished it because no one gave me any hope or believed that I could do it alone. I learned through years of trial and error how to compensate for my learning and social problems. I did very well and everyday I learn to compensate for something else. I know I will always succeed, because I will always figure out a new way to compensate for any problem this comes up, whether it be at work, or graduate school or any aspect of life.

I'm sorry I got way off of the topic, but I needed to get this out. Thanks for listening.

Stefan



## SAC, from page two

identify potential donor organizations to help support new investigations in K.S. research.

Strategies were proposed to begin the above processes. Provided that travel funds are available, the SAC will meet at least annually at the time of the National Klinefelter Syndrome and Associates meeting. Interim meetings will occur by mail and teleconferencing.

## Doug's Report, from page four

parents that they felt Doug was not a candidate for hormone replacement therapy, despite what the conference physicians had recommended. The local doctors expressed concern that he may become violent if they increased his testosterone levels. In early September he was admitted to a private psychiatric facility because his family was afraid he had become a danger to himself. The doctors prescribed anti-psychotic drugs. He was discharged, then re-admitted one week later to a state facility, where he is at the time of this writing. Our thoughts and prayers are with his family during this emotional and frustrating time. If you would like to write to Doug or his family please send your correspondence c/o: KSA, P.O. Box 119, Roseville, CA, 95678-0119 Attention: Doug/Carol

## Does Your Company Have a United Way Campaign?

Did you know that you can contribute to Klinefelter Syndrome and Associates through your company's United Way campaign? While we are not a United Way affiliate, you can still contribute by listing our complete name and address on your United Way contribution form. Often companies provide matching funds that make your non-profit contribution dollars go farther! Thank you for your continued support.

*The past is history.  
The future is a mystery.  
Today is a gift.  
That is why we call it:*

***"The Present"***

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## **Families Wanted for Klinefelter Syndrome Study**

A new study is being performed by Brenda Eskenazi, a professor at UC Berkeley School of Public Health and Andy Wyrobek, a researcher at Lawrence Livermore National Laboratory.

They are currently researching whether the rate of aneuploidy (that is, extra chromosomes) in the sperm of fathers is different depending on whether the father did or did not contribute the extra "X" chromosome.

They are looking for families who have a son six or under, with a karyotype of 47-XXY and no vasectomy for the father. The father, mother and son will be asked to participate in the study.

Klinefelter Syndrome and Associates applauds this research and appreciates your support.

**Please contact  
Melissa Aylstock, Klinefelter Syndrome and Associates  
(916) 773-2999**

*All calls are confidential!*

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