

Newsletter: Klinefelter's Syndrome

Support Group: Victoria (KSSGM)

WINTER, 2001

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What's this?

Eileen Grichting

I spoke to a couple of people at the **KSSG/V** Christmas Picnic and offered to do a trial run of a Newsletter. I am retired and have time- I also have a computer and printer at home. There are a few dollars in the **KSSG/V** 'kitty' to cover costs for this year only. After two or three issues, we can ask the readers whether they want to 'subscribe'. Then it will be time to ask subscribers what they want in the Newsletter, and to decide on an editorial board from **KSSG/V**.

Tanya and Jim Yard - whom most of us know- gave me a list of the addresses of people who have contacted them over the past few years... and that is why this issue has arrived in your mail box!

Why have a Newsletter

The **KSSG/V** is a loose grouping of very busy people who live at considerable distances from one another. A Newsletter can be a useful way of

- keeping up connections,
- sharing information,
- identifying common problems and
- taking unified action if needed.

Keeping up connections

Jim and Tanya Yard organised the first meeting of the **KSSG-V** several years ago. There were many group meetings. Perhaps the original group members can pool their memories and give us a

history of those years. Now, however, it appears that most people do not have the time to attend meetings. Time will tell whether a Newsletter like this will help people keep up connections.

Sharing information

For starters, I offered to pull information together from the many Klinefelter discussion groups on the Internet.

In this issue I have included- in the green boxes- the names of as many Klinefelter Internet discussion lists as I have been able to find, together with descriptions and instructions for subscribing.

If you know of some others, please send the addresses in & we'll print them.

We all know that knowledge about KS is a bit thin on the ground. We often meet GPs who have never heard of the condition. They certainly are not up-to-date on treatment- neither HRT nor how and what else to monitor in the health of a person with KS.

It is generally up to us to locate information and bring it to our doctors. Many in this group have gone to a lot of trouble to gather information on KS.

No sense in letting all that work go to waste! Share your 'finds' with the rest of us through this Newsletter.

Sharing experiences too can be helpful. For example, two Australian men with KS have tried out the Androderm 'patch'. - and have gone back to injections. Others swear by the Patch and loath injections. It would be good to hear from readers about their experiences.

Enclosed with this Newsletter is a brochure I downloaded from Vaughn Hambley's Website (www.47xxy.org).

We hope to print up several hundred of these brochures for

- 1. professional staff working with
- 2. Adults with KS
- 3. parents of children with KS.

Vaughn Hambley did a lot of work in developing the brochure - and he makes it freely available for us to print and use.

What a great way of sharing the information he gathered!

By the way, if you have not already discovered his Website, you are missing something!

Identifying common problems

One common problem is finding the right form of HRT for each person.

What works for one does not necessarily work for another. Switching from one form of delivery of Testosterone to another can be difficult and confusing.

Solutions can be found, but by the time you find the solution you have had more discomfort than is fair.

For example, instructions for using the recently released Androderm Patch were unclear.

Some people got huge bruises and irritated skin. Others could not keep the patch in place.

Finding the right ointments for the irritation and bandages which teenagers are willing to wear to hold the patch takes a lot of effort.

KS Email Discussion lists

XXNOY

This is a list for parents of xxy sons, or other sex chromosome anomalies. Learning and supporting each other is the goal. It is a restricted list and the moderator must approve members.

Group Email Addresses

For more information:
<mailto:Lindina2@aol.com>
 Post message:
 XXYNOY@yahoogroups.com
 Subscribe:
 XXYNOY-subscribe@yahoogroups.com
 Unsubscribe:
 XXYNOY-
 unsubscribe@yahoogroups.com
 List owner:
 XXYNOY-owner@yahoogroups.com

Group Info

Members: **136**
 Founded: **Jul 10, 1999**
 Language: **English**

Group Settings

- Listed in directory
- Restricted membership
- Unmoderated
- All members may post
- Archives for members only
- Email attachments

xxnoy2

A "support/discussion List" for Moms and/or Dads whose son's genetic signature is XXY (or a variation thereof) and whose son's age is between onset of puberty and adulthood.

For more information: mwksa@aol.com
 Post message:
 xxynoy2@yahoogroups.com
 Subscribe:
 xxynoy2-subscribe@yahoogroups.com
 Unsubscribe:
 xxynoy2_@yahoogroups.com
 List owner:
 xxynoy2-owner@yahoogroups.com

Group Info Members: 74

Founded: **Nov 9, 1999**
 Language: **English**

Group Settings

- Listed in directory
- Restricted membership
- Unmoderated
- All members may post
- Archives for members only
- Email attachments are permitted

thexxynetwork

This list is for the 1:500 males worldwide that are effected by the karyotype of 47xxy / Klinefelter Syndrome and or the variants. This list is run by those affected and those that are directly connected to those affected, be it a parent, spouse, friends and or professionals. We communicate on this list for support and in an effort to educate each other. This list is not moderated; it is patrolled to assure that those with other than positive intentions are not able to hurt those on this list.

Group Email Addresses

For more information:
 mailto:xxynetwork@iwon.com
 Post message: thexxynetwork@yahoogroups.com
 Subscribe: thexxynetwork-
 subscribe@yahoogroups.com
 Unsubscribe: thexxynetwork-
 unsubscribe@yahoogroups.com
 List owner:
 thexxynetworkowner@yahoogroups.com

The **AAKSIS** email List has been formed to provide discussion, support, and fellowship for the international community of those medically diagnosed as being XXY (and variants), their supporters, family members, spouses, medical, and psychological advisors.

For more information: <http://www.aaksis.org/>
 Post message: AAKSIS@yahoogroups.com
 Subscribe: AAKSISsubscribe@yahoogroups.com
 Unsubscribe: AAKSIS-
 unsubscribe@yahoogroups.com
 List owner:
 AAKSIS-owner@yahoogroups.com

Group Info

Members: **158**
 Founded: **Apr 5, 2000**
 Language: **English**

Group Settings

- Listed in directory
- Restricted membership
- Unmoderated
- All members may post
- Archives for members only
- Email attachments are not permitted

Klinefeltersyndrome

a new and gay friendly list for males who are diagnosed with Klinefelter Syndrome, for postings, discussions, and exchange of information and education.

Post Klinefeltersyndrome
 message: @yahoogroups.com
 Subscribe: Klinefeltersyndrome-
 subscribe@yahoogroups.com
 Unsubscribe: Klinefeltersyndrome-
 unsubscribe@yahoogroups.com
 List owner: Klinefeltersyndrome-
 owner@yahoogroups.com

Group Info Members: 18

Founded: **May 6, 1999**
 Language: **English**

Group Settings

- Listed in directory
- Open membership
- Unmoderated
- All members may post
- Public archives
- Email attachments are permitted

What about those Patches?

Faulding Pharmaceuticals released Androderm Patches in Australia last November. Here there is only one kind of patch - the Androderm Patch. Elsewhere there are two types- Androderm and Testoderm.

How do the Patches compare with Injections? Below is an overview of the pros and cons for each method, which I compiled from postings in several E-mail discussion lists.

Patches

Pros:	Cons:
<ul style="list-style-type: none"> • Patches make it easier to regulate testosterone levels 	<ul style="list-style-type: none"> • expensive
<ul style="list-style-type: none"> • mood swings are rare 	<ul style="list-style-type: none"> • possible severe skin reaction,
<ul style="list-style-type: none"> • cholesterol and red blood cell count are not affected 	<ul style="list-style-type: none"> • often requires adhesive tape to make them stick
<ul style="list-style-type: none"> • Patches do not cause liver disease 	<ul style="list-style-type: none"> • you have to fuss with them every day
<ul style="list-style-type: none"> • patient takes care of himself 	<ul style="list-style-type: none"> • difficult to hide when wearing shorts and t-shirts
<ul style="list-style-type: none"> • application is painless 	<ul style="list-style-type: none"> • some do not reach high enough levels of Testosterone

Injections - two types but little difference

Pros:	Cons:
<ul style="list-style-type: none"> • inexpensive 	<ul style="list-style-type: none"> • some people get mood swings and emotional upsets
<ul style="list-style-type: none"> • no skin problems 	<ul style="list-style-type: none"> • cholesterol will increase
<ul style="list-style-type: none"> • treatment is every week or every other week instead of daily 	<ul style="list-style-type: none"> • red cell count may increase
	<ul style="list-style-type: none"> • can cause liver disease
	<ul style="list-style-type: none"> • testo levels hard to regulate
	<ul style="list-style-type: none"> • must either go to doc's office or learn to self-inject

Comparison between types of patches:

(1) ANDRODERM

Pros:	Cons:
<ul style="list-style-type: none"> • very effective 	<ul style="list-style-type: none"> • more than half of men using it get skin problems ranging from unpleasant itching to painful skin ulcers
<ul style="list-style-type: none"> • comes in two strengths 	

(2) TESTODERM: two types: note: not available in Australia

Type 1: sticks only to scrotum

Pros:	Cons:
<ul style="list-style-type: none"> • very effective 	<ul style="list-style-type: none"> • must shave scrotum weekly with razor blade
<ul style="list-style-type: none"> • skin problems are rare 	

Type 2: sticks anywhere except scrotum

Pros:	Cons:
<ul style="list-style-type: none"> • very effective, • severe skin problems are rare 	<ul style="list-style-type: none"> • compared to the other patches, none

Care of the Patch site: the Gospel according to Faulding Pharmaceuticals

I wrote to Faulding with questions about using the Patches. Mrs Seegar replied:

"Skin irritation, topical corticosteroid creams in response to your question, topical corticosteroids can be used to treat skin irritation associated with Androderm patches. You should ask your chemist for an over-the-counter preparation of topical corticosteroid cream. There a number of these available, and your pharmacist will be able to recommend one. Triamcinilone acetonide (Aristocort, manufactured by Lederle) is only available on prescription.

Patches, sweating

Generally, Androderm patches can remain in place during showering, exercise etc. However, they may become dislodged with heavy perspiration. Patches should be applied late in the evening (at about 10pm). If a patch dislodges before mid day, a new patch should be applied to the same site. If a patch falls off after mid day, wait until the usual evening time and replace with a new patch in a different site.

I hope this information will be useful to you. Please do not hesitate to contact us again if you require further information."

A Nurse explains why....

Ron St Aubyn, from Louisiana, has been in nursing over twenty years- and himself has KS. He sends a more complete explanation for us on the use of steroid creams:

"The Triamcinilone acetonide cream has to be applied in a very thin coat, before applying the patch, and not to overlap where the adhesive of the patch will be. The irritation is caused by the high percentage of alcohol, used as a vehicle for the testosterone to pass through the skin. It is the drying out of the skin in those areas that causes the intense itching. Udder cream, butt balm, and the like, are used to replace the moisture, to those areas after the patch is removed. The cortisone creams are of no use to the rash, after the patch is removed. It has to be applied before. There is also a decrease in absorption of testosterone, with the cortisone cream, since most of that cream has petroleum jelly or some type of wax derivative added as part of the emulsion. Triamcinolone cream is usually prescribed with the Androderm patch. Good luck, *Ron St. Aubyn*"

KSvariant4parents - A Klinefelter Syndrome variant support group for parents

Join this group if your child has any variation of Klinefelter Syndrome other than xxy. This group will provide parents with support and understanding from other parents with similar need. If you are a xxy parent, please also join the xxyparentnetwork list, also located at egroups.

Group Email Addresses

Post message: KSvariant4parents@yahoogroups.com
Subscribe: KSvariant4parents-subscribe@yahoogroups.com
Unsubscribe: KSvariant4parents-unsubscribe@yahoogroups.com
List owner: KSvariant4parents-owner@yahoogroups.com

Group Info

Members: 20
Founded: Jul 27, 2000
Language: English

Group Settings

- Listed in directory
- Restricted membership
- Unmoderated
- All members may post
- No archives
- Email attachments are permitted

XXY+ ADULTS

This list is designed especially for men with KS but family members may also subscribe. . Each person wanting to subscribe will be asked why they want to belong. There are many active and well-informed subscribers to this list. When a subscriber posts a question, he can count on receiving many replies and lots of good information and support. However, family members seeking support should, in general, look to the email discussion lists designed for parents or for partners.

Post message: XXY+ADULTS@HOME.EASE.LSOFT.COM
Subscribe: LISTSERV@HOME.EASE.LSOFT.COM In the body of the message write SUBSCRIBE XXY+ADULTS
Unsubscribe: LISTSERV@HOME.EASE.LSOFT.COM In the body of the message write SIGNOFF XXY+ADULTS
To get one email a day (called a Digest) :
LISTSERV@HOME.EASE.LSOFT.COM In the body of the message write SET XXY +ADULTS DIGEST

XXY+PEDS

Another email list is parents. Follow the instructions for XXY+ADULTS- substituting XXY+PEDS wherever XXY+ADULTS appears.

More on creams and bandages which make the Patch work

There are two kinds of cream needed- a steroid cream just under the business part of the patch, and another cream to sooth the skin irritated by the adhesive.

The cream to sooth the skin irritated by the adhesive is a type developed for use on cows' udders! It seems to be very effective- when I finally found a source for it in Melbourne, the sales person told me they sell more to people for their personal use than dairy farmers purchase for their herds. It can be purchased at agricultural supply stores or for those in the Western suburbs, at the University of Melbourne Veterinary Clinic in Werribee.

For vigorous boys and men, the patch often works itself off. Where to find something that secures it without making you look like you have been through the wars? Back to veterinary suppliers! The kinds of bandage used on racehorses come in many colours- and are often used by their riders as well. Teen-agers are much less likely to object to a coloured bandage- or so some parents report.

A last bit of advice

"Rotate the sites of the patches" a local pharmacist warned. Putting it on the same place every day almost guarantees irritation.

And do talk to your GP or Endocrinologist about ideas about or problems with patches and injections. This Newsletter does not have any intention of giving proper medical advice. The aim is to give sources of information. It is up to you to examine the information and decide with your GP or Endo what you are going to do

The End!

Finally we come to the end of the first Newsletter. Let me know what you think of it. My postal address is on the first page. My email address is girchting@sub.net.au. The telephone number is 03-9731 0338.

Talk to me about ideas for the Spring Issue.

Eileen Grichting

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