



XP Support Group Reg. Charity No. 1075302



Jeans for Genes Campaign, Reg. Charity No. 1062206

Jeans for Genes 2006

As announced in the newsletter the XP Support Group has been selected as a guest charity for the 2006 Jeans for Genes (J4G) Appeal. It is an annual national appeal to everyone to wear jeans or denim for one day instead of their normal uniform or working clothes. As it is always on a Friday it means a fun day and a change from the norm for most people who go to work or school in smart clothes. Everyone who puts on their jeans is asked to donate to the appeal - £1 for schoolchildren, and £2 for those taking part at work. This year the date is **Friday 6th October 2006**, and this year's theme is **Dress to Impress** and make an impression on a child's life – so it isn't just jeans but it should be denim.

So why does J4G need to raise money? One child in 33 in the UK is born with a genetic disorder. We all probably know someone who is affected but many genetic disorders, including XP and other light sensitive conditions, currently have no cure. This situation will not change without the money raised by appeals like J4G. The money is used in two ways; to fund much needed research projects, and secondly, to support affected families through day-to-day services, counselling and advice, local clinics, respite care, away days and specialist nurses. In the case of the XP Support Group J4G want to help us to provide more and better counselling to families and also with running our support effort.

The J4G appeal is organised by four main charities led by the Great Ormond Street Hospital Children's Charity. Each year they select a small number of guest charities who will share in the proceeds of the appeal based on the projects for which they need funding. This year there are six guest charities including the XP Support Group. In return for the help we will get from the J4G Appeal we have to try and help to make the Appeal a success as best we can.

So how can the Members of the XP Support Group help? In lots of ways and it doesn't matter if you are a patient, a parent or sibling, a medical person, or just a friend. Everyone can do something. We will send you more details in July with a J4G Newsletter but in the mean time here are some ideas for you to consider.

- Spread the word. It's as easy as telling friends, family, school mates, work colleagues, people you do sport or other activities with, etc. Whatever is listed below they can also do, and that way we can turn the membership of XP into an army of thousands, all helping a little bit.

- Find out if your school or work place has already supported the J4G Day in earlier years by allowing the wearing of jeans and the collection of the £s. If they have then encourage them to do it again this year. If they haven't done it before then see if you can persuade them to participate this time, and they can register with J4G in June.
- Talking of schools you or your friends could volunteer to do one or two talks at schools in your area. You won't have to prepare anything. J4G make available a presentation which can be tailored to incorporate your own story or details about XPSG. The talks are generally done at morning assembly and only last 10 to 15 minutes. These talks are a very important part of J4G's effort to educate youngsters about the impact of genetic disorders and secure their help in supporting the appeal. If you would like to volunteer then let us know during May so we can get you more information and get you registered.
- An excellent way of involving your local community is to contact your local schools, businesses and clubs, local council, leisure centres, in fact anywhere a number of people could take part in a group activity like J4G Day. If they register with J4G next month (details to follow) they will then be sent a fundraising pack and posters to help with the day.
- Alternatively, if they don't want to register as a supporter but are happy to have flyers, posters, and a collection bucket then you will be able to organise that. This can be done with shops, pubs, and GP surgeries.
- To help raise awareness of genetic disorders and the J4G Appeal you might be prepared to talk to the press or radio about your personal story as a patient, parent, or sibling. Some of our member families have already done this, but this time we would like to ask for as many volunteers as we can get. It is all arranged very carefully and you can remain anonymous if that is what you want. The stories are used by the local press particularly to raise awareness of J4G Day as it approaches. If you would like to help then let us know in May so we can get you registered and more information in June.
- You and your friends could sell the J4G £1 items – badges, mobile phone dangles, and key ring tokens. Once the Appeal campaign is launched you will be able to order these items on a sale or return basis through XPSG.
- Organise a fundraising activity. There are lots of possibilities to choose from and you can often get sponsored for almost anything so long as it is safe. Street parties, fun runs, walks, bring & buy sales, barbecues, and so on. Then the trick is to get your local newspaper, parish magazine, etc to print a story which publicises both your event and J4G Day.
- Collect donations and we can send you the giro slips you can use to pay it in at your local bank or building society for credit to J4G.

So, lots of ideas. If you would like to volunteer either to give a school talk or two, or to talk to the media, please contact either Sandra Webb at XPSG or Chris at 01276 479684 or cjardine@btconnect.com.