

Trichothiodystrophy, Xerodermapigmentosum, Cockayne Syndrome Trust Fund .



The Friends of Sammy-Joe Foundation

April 12th The Launching Event .

2008

April 24 th 2008

Welcome everyone to our first official Newsletter .

We have had an exciting three months .

The Launching of The Friends of Sammy-Joe Foundation took place at the Turf Club on April the 12th , it was a huge success . Thank you to everyone who came along , had fun , ate the mountains of food , proudly provided by one of our many sponsors .

We would love to thank All of our sponsors , because without them this event could not be successful .

On behalf of The Friends of Sammy-Joe Foundation .I would like to thank you all for your generous Donations and for attending this very special event You are all generous and kind hearted people, without your support our event could not have been a success Your support helped us to raise over \$7,000. Your commitment to helping our Launching event in our community is sincerely appreciated.

I am grateful to you for your gift of friendship, your advice ,your continuous wisdom and for all your support , I feel blessed to have you all in my life . Thank you for all that you do in supporting us with achieving great success for our Charity and what you do for Sammy-Joe and my family .Each year The Friends of Sammy-Joe will continue to advance its mission of Creating a Better Life for the families

and children of The Friends of Sammy-Joe Foundation. Through our programs and Charitable events we have seen many lives changed for the better., in a short time.

In particular The Friends of Sammy-Joe families have received help in the past three months

The goal of The Friends of Sammy-Joe Foundation is to continue to make a difference in the Lives of those affected by Trichothiodystrophy, Xerodermapigmentosum and Cockayne Syndrome .With the help of donations from supporters such as you we will continue to see improvements in their lives .

Thanks again for your generous support of our efforts to improving the lives of those affected by these illnesses and in helping to Create a Better Life for them

I would also like to thank the committee members for all their help in organising this event and to all the fundraising committee members , also to our many volunteers and generous kind hearted friends that put in an enormous effort into making the night a wonderful event . (Also to my husband Joe for selling tickets)

This will be one of our many events and judging by the photos , everyone had a great time .



SPECIAL PROJECTS and Events

Special Grants received

Genetic Support Network of Victoria Special Projects Grant \$400

Thank you so much to the GSNV for approving this for us , we will be using the money funded for Business cards and posters , this will help us to continue to Raise Awareness .

Don't forget our next meeting is on the first Wednesday Night in May at Heidi s house , please let me know as soon as possible if you can attend .

On April the 13th I attended the GSNV FAMILY DAY AS PART OF THE COMMITTEE , IT WAS AN HONOUR TO HAVE SPENT ALMOST A WHOLE WEEKEND WITH THE LOVELY AND FOREVER WISE LOUISA

PICTURED HERE IS Louisa ,Leah and Marjorie

The GSNV IS a vibrant and active organisation which aims to maintain a thriving network committed to promoting the interests and wellbeing of people affected by Genetic conditions.



Photos taken at the launch night



The Girls From Craigieburn Amcal Pharmacy had fun on the night .



The Happy People from Kayser Hoisery



Me , Salv and Rachelle Rose



Luisa , Simone and Me



Luisa ,me Anne Sash and Anne Edwards



Peter ,Joe ,Tony and Erica

Sammy Joe Liistro Delfin Lend Lease Pergola Structure
13 Hursley Ct Craigieburn

Delfin Lend Lease Craigieburn approached Naturform in November 2007 to assist in the design and construction of an outdoor play center for Sammy Joe Liistro who suffers from the degenerative disease TTD for his use and for the use of others with similar disabilities. Sammy Joe is basically allergic to sunlight so our brief was to construct an outside play centre adjoining the family home to ensure that no light could penetrate in, as well as making it functional for the other family members The Delfin Lend Lease design team in conjunction with Naturform Landscape contractors and Commercial Builders, Urban Edge Landscape Architects, Westweld Steel suppliers and fabricators and Greg Schofield and Associates Structural Engineers came up with a design that would facilitate all the necessary requirements

Our task then was to request from our Contractors and Suppliers for rebates or donations for either time or material. In conjunction with various philanthropic organizations and government agencies the Delfin project has raised over \$100,000 in donations and pledges to date The project will exceed a net value of \$150,000 The works have commenced in March The existing backyard has been completely demolished Excavations and footings for frame will be completed by 1st week in April The Frame will be installed by the 2nd week in April Subsequently the numerous additions will be installed such as Remote controlled roller shutters Therapeutic spa; Rubber matting floor Paving area; Trampoline; Wheel chair ramp; Air-conditioning and Heating system UV sensitive lights etc Part of the play centre project will include a completely revamped landscape to the rear of the property which will include Adult retreat; Storage facility for games, and toys; Trees plants and garden beds Turtle habitat; Basketball area; rainwater tank; outdoor lighting etc The donations have also included scholastic and therapeutic equipment relevant to the sufferers of TTD such as Drawing boards;; ball pool; therapeutic mats; exercise bike; tread mill; swing chair; chalk board; tables and chairs; etc



The boys hard at work ankle deep in concrete.



Spreading the Crush rock ready for the concrete



The Structure is in stage 4
It is estimated at being complete around
May 26th 2008.

Whats New And The Support Group News

At present the Support Group is on hold until the structure is completed .

We will be putting in place some guidelines and rules and also looking into applying for more grants so that we can run the group for two years or more , I will be busy applying for lots and lots of Grants so wish me luck !!

The Benefits of the group will be endless , firstly it will be a wonderful and enjoyable place for the children and their families from The Friends of Sammy-Joe Support Network to be able to attend without the added worry of being exposed to

light .

Thanks to Delfin and Naturform and of course the endless list of sponsors , this beautiful PAVILLION will be a safe place to play in.

Now for more news

Because of the endless Generosity of our sponsors , we were happy to help our families in the past couple of weeks , here is a photo of Victoria and Khalil , our newest members

Look how happy Inaam is as well , its wonderful to know that we all have each other to support .

Thank you to The Friends of Sammy-Joe Foundation



Melissa and Marianne are our gorgeous Twins , these beautiful 12 year old girls are our newest members . because of our event we were able to pay for some of their medical expenses and we will also continue to help them with their requests .

Please continue to give generously to the fund , because with your help and support we can continue to CREATE A BETTER LIFE for our very special children and young Adults of THE FRIENDS OF SAMMY-JOE GROUP .



FUNDRAISING IDEAS

The Friends of Sammy-Joe Foundation

If anyone would like to make a direct deposit to the Friends of Sammy-Joe Foundation, the details are as follows:

The TTD, CS , XPD TRUST FUND,
FRIENDS OF SAMMY-JOE FOUNDATION.
COMMONWEALTH BANK, CRAIGIEBURN,
VICTORIA, 3064
063 875 1029 7747

for Trichothiodystrophy Xerodermapigmentosum Cockayne Syndrome TFund

Our ABN number is 33143598689.

We are a charitable trust and we do issue receipts.

Please let me know if you have deposited some funds and send me your address to sammyjo2@bigpond.com.au or call me on 0407 558 151, and we can send you a thank you note as well as a receipt for payment. Please do make sure you let me know if you do deposit, this way we can acknowledge your donation.

Thank so much .

Hugs

Maria Liistro

The money deposited will go to helping Children and young Adults still surviving with this condition and in helping to Create a Better Life for them.

**DO YOU HAVE ANY FUNDRAISING IDEAS
YOU WISH TO SHARE WITH US , COME AND JOIN OUR
FUNDRAISING COMMITTEE**

CALL Maria 9305 61 82 for more information



Smile a while and give your self a lift , raise your hands to the one you love the best .

**Whatever your cross,
whatever your pain,
there will always be sunshine,
after the rain....
Perhaps you may stumble, perhaps even fall;
But God's always ready, to answer your call....
He knows every heartache, sees every tear,
a word from His lips, can calm every fear...
Your sorrows may linger, throughout the night,
But suddenly vanish, by dawn's early light...
The Savior is waiting, somewhere above,
to give you His grace, and send you His love.
May God fill your day with blessings**

THE FRIENDS OF SAMMY-
Joe Foundation

The Trichothiodystrophy ,
Xerodermapigmentosum ,
Cockaynes syndrome Trust
Fund

ABN 33 143 598 689

WE ARE A CHARITABLE

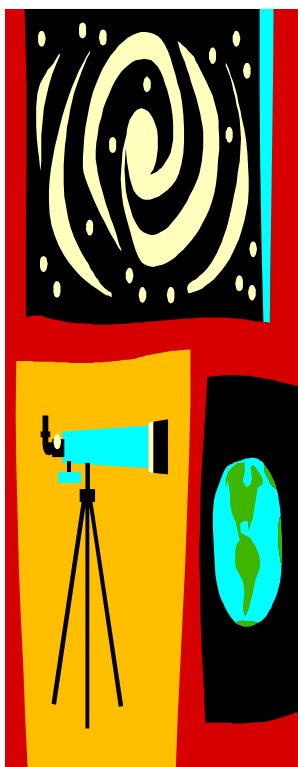
TRUST AND WE DO HAVE
DGR STATUS

Please call MARIA 9305 61 82

▶ OR HEIDI

0408033757

We are on the web
[http://www.vp-it.com.au/
sammyjoe/](http://www.vp-it.com.au/sammyjoe/)



The Foundations mission statement

To Create a Better Life I

To help Provide Financial assistance and other assistance to people that are affected by this illness and other DNA repair disorders .

To enhance and maintain the quality of life of children and young people and or / adult with high needs due to Trichothiodystrophy , CS,XP and /or other DNA Repair Disorders,

To Work in partnership with the families and communities to promote better understanding of the effects of the Trichothiodystrophy , CS and XP

.Optimum participation in life , to ensure that quality of life is enhanced in order for the child /or young person and or/ adult affected by the illness can have an active part in our community .

-Maximisation of abilities and empowerment of all family members where there are young people and or / adult who have been affected by Trichothiodystrophy And or / XP , CS and other DNA repair disorders through the provision of

Innovative responsive and holistic supportive developmental services driven by family priority and situation due to the condition. Eg, environment needs to be made safe, quality of life needs to be enhanced, and medical needs need to be addressed.

To allow families with Children and young people and or / adult with Trichothiodystrophy, CS , XP to travel to hospital s that have doctors that have researched this illness world wide and / or interstate from their place of residence .

Trichothiodystrophy ,XP and CS due to medical expenses and Treatment .

To Provide support by continuing to run the support group for the Families regarding the emotional aspect of having a child or young person/ adult with Trichothiodystrophy ,XP and CS

To allow the relief of financial hardship that has been placed on the families that have children and young people and or / adult affected by Trichothiodystrophy , CS AND XP AND /OR other DNA Repair disorders in Australia

April 9th 2005