



# The Friends of Sammy-Joes Newsletter



**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**  
**0408 033 757**

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sammy Joe/](http://www.vt-ip.com.au/sammyJoe/)**

## THE STORY BEHIND THE FOUNDATION

The Friends of Sammy-Joe Foundation was founded by Sammy-Joe's mother Maria Liistro. The Foundation aims to assist sufferers of rare genetic disorders, including Trichothiodystrophy (TTD), Cockayne Syndrome (CS) and Xeroderma Pigmentosum (XPD).

The Foundation seeks to raise funds to enable sufferers to create a better life, by providing financial assistance for costs including medical bills and other related expenses including solar protective clothing, sunscreens, necessary home alterations, and medication aides and equipment which are not covered by government assistance.

The goals of the project, "Create a better life" are:

- \* Raise awareness of the rare genetic disorders of TTD, CS and XPD and prolong life expectancy.
  - \* To find other sufferers of the rare genetic disorder and to aid in early diagnosis.
  - \* To alleviate the financial hardship of families due to children/young adults diagnosed with genetic disorder.
  - \* To reach out to families that are socially isolated and to be included in community activities.
  - \* To provide parent supported playgroups in an environment that is safe from the sun.
- The objectives of the goals are to:
- \* To build on the capacity

of a family that has a child/young adult diagnosed with TTD, CS and XPD to help prolong life expectancy by creating a better life.

- \* To hold fund raising events through the friends of Sammy-Joe foundation.
- \* To support the establishment of social networks amongst the community and parent supported playgroups
- \* To provide a solar pro-



**Maria Liistro and her son  
Sammy Joe**

ected area so that the children/young adults can experience social connectedness with families and children in the community.

The strategies of the objectives are:

- \* To provide families with information about the illness through established web site, online support group, ongoing newsletters and information fliers, which will provide knowledge on the illness and support families to build on their skills to create a better life for the children/young adults.
- \* The Friends of Sammy-Joe foundation will hold ongoing fund raising events to support the families that are affected by financial hardship.
- \* The foundation will adver-

tise and invite families to the solar protected structure by promoting awareness through community connections, such as Local government groups and other health organizations.

- \* To outreach nationally to socially isolated families and to provide information and funds to help strengthen the family unit and link to community organizations.

The overall outcome is to unite the families that are socially isolated due to the illness, to provide ongoing support and to fulfill a sense of belonging within the community, to create a better life.

The project will continue to be sustainable through the support of local and wider community organizations. The friends of Sammy-Joe foundation will continue to raise funds to help support the families to manage the ongoing struggles that are experienced by having a child/young adult with the illness.

The impact of the project "Creating a Better life" will be measured through ongoing communications with the families. The friends of Sammy-Joe foundation will respond to the arising needs locally and nationally through evaluations and discussions with the wider community groups.

The Friends of Sammy-Joe Foundation was endorsed to help Create a

## THE REALIZATION CONTINUES



better life for individuals who are suffering with TTD,CS and XPD.

There is no other charity that caters for the needs of these individuals in the whole of Australia. The friends of Sammy- Joe foundation will continue to seek and raise funds to support the families that are suffering with the illness, with the support of the committee members guided by Maria Liistro, CEO.

These children/young people and their families spend a huge amount of their time indoors. This affects quality of life, behavior, and links with family, friends and the com-

munity.

The Friends of Sammy-Joe Foundation and social network will work together at connecting families within the areas of the State of Victoria , to begin with ,forming strong bonds with community groups by raising awareness on all the conditions relating to Sun sensitivity .



### Media Release : Local boy comes out to play

A local boy allergic to sunlight will be able to step outside to play for the first time as Delfin Craigieburn, Naturform Pty Ltd and other generous Melbourne businesses join together this Thursday 12 June from 12 noon to celebrate the completion of his own special play centre. Delfin and its 25 partners from local and major businesses have completed construction on an outdoor play area for Sammy Joe Liistro, who suffers Trichothiodystrophy (TTD), a rare genetic disorder which causes skin sensitivity and allergy to UV rays and fluorescent light. The play area and surrounding landscape, worth more than \$180,000, will enable Sammy-Joe's parents and carers to control and limit the amount of UV light entering the room. Sammy-Joe's mother Maria Liistro said the play area would not only allow Sammy-Joe To play outdoors without the danger of exposure to UV rays, but would also provide a place of recreation and enjoyment for other sufferers of TTD. Sammy-Joe is so excited to have his own special place to play, and to be able to share this play area with so many of his special friends is something he is even more excited about, Mrs Liistro said. Delfin secured more than \$XX,000 worth of donations from generous contractors and suppliers who have worked closely with Delfin on its projects. Craigieburn Project Director Tom Trevaskis said the project was a fantastic combined community effort, and would allow Sammy-Joe to enjoy some of the activities many children took for granted. We are thrilled to celebrate the completion of this project with Sammy-Joe, his family and the many people who have helped make this play area possible," Mr Trevaskis said. We build a lot of playgrounds in our communities, and it's a privilege to build a special area that Sammy-Joe can enjoy as well" Craigieburn is being developed by Delfin Lend Lease, Australia's largest developer of master planned communities, with 16 trading projects nationally.



Thank you from the Liistro family

THE WONDERFUL TEAM  
FROM DELFIN

# THE OPENING OF THE FRIENDS OF SAMMY-JOE PAVILLION

The Delfin Lend Lease Community Project this year was the Opening of the Pavilion at my house, the event was great, we had balloons, show bags, a clown and face painting, the children and their families enjoyed themselves, the Pavilion was full of happy smiles, the place was full of cheer.

All went well, the weather held up and people gathered together and enjoyed a sausage sizzle lunch, thanks to Matty and Ben for handling the BBQ.

Thank you to Tony Jackson and Jamie Zoch from Naturform who also came to help out. It was great seeing you playing amongst the children and keeping them entertained with the juggling and the hoops.

Thank you to Tom Trevaskis, Anne Jessop, Marita Loel and their wonderful Team at Delfin Craigieburn for catering the event. We had a great time. Overall it was a great day.

## PHOTOS OF THE DAY



**THE OFFICAL OPENING**



**WITH SAMMY JOE HELPING**



**TONY AND TOM HAVING FUN**



**OUR WONDERFUL COMMITTEE**



**THE TWINS HAVING FUN**



**WHOS  
HAVING  
MORE  
FUN  
HERE**



# The Friends of Sammy-Joes Newsletter

## MORE PHOTOS OF THE DAY



**GROUP HUG**



**THE CURTIS FAMILY WITH MADELINE**



**LOVING MOTHER AND SON**



**THE BEAUTIFUL CHILDREN**

### The Support Group

We are going to be running a Parent supported play group, Once a month the children of the group are going to be coming over with their parents and we will have a fun filled three hours, this is a way of connecting us together into the community, we will also be trying to run Music therapy, art therapy and other events for the group. we will need sponsorship and some funding to enable the groups to continue. We are in need of Taxi Vouchers, musical instruments, art and crafts materials and also I would love to run some relaxation therapy for the children also, some relaxation massages and aroma therapy sessions. At times we would like the Clown and face painter to come, and also some other forms of entertainment. Balloons, gifts and fun things, I really would like the kids to enjoy themselves fully whenever they come. We had my friend Jerildene come over with her two dogs called Micky and Alice, this has also shown us a way of introducing pet therapy to the children, so at times we can even have a hobby farm come out and also the reptile man, I would love to see the look on the children's faces, all we need to do is get some funding.

**Maria Liistro**



# THE LIISTRO FAMILY STORY

## Maria's Story

My son Sammy-Joe has Trichothiodystrophy and was diagnosed after 13 difficult years. He is now 19 years old. He was born by emergency caesarean section at 38 weeks. He was smaller than expected for a child at that age, and his head was 26% smaller compared to the norm. He was born with curly, brittle hair, short and sparse, small eyes, dry skin and very floppy. He weighed 5lb 2oz and lost a dramatic amount of weight in the first two days of his life.

He lost all of his hair after having a temperature, while having a bath in the hospital. He had difficulties suckling, and failure to thrive. Because of his poor immunity, he has had many stays in hospital throughout his life undergoing extensive tests, Gam-maglobulin treatment, surgery and rehydration. He has lactose intolerance, ataxia, speech delay, autistic characteristics, poor weight gain and stunted growth. Certain sounds and lights affect him, triggering him to scream as if in pain, which I now believe at times truly hurts him.

He is photosensitive to the light and refuses to wear short sleeves due to the sun hurting his skin. For years I couldn't understand why he wanted to wear long sleeves on a 40 degree Celsius day. Now I know why.....he cannot be exposed to too much sunlight, he is quite fragile and sometimes unsteady on his feet, and often faints when he is unwell. Aside from all the trials and battles in his life, he is a happy child that has a passion for books, videos, nursery rhymes, the Muppets, animals, stuffed toys and James Hird from the Bombers. My sister-in-law once said, *"Imagine if everyone had the same passion for things, or loved the same way Sammy-Joe does, this world would be a better place"*.

I have often been asked what does the future hold for my son's life, and I would be lying if I said it doesn't scare me. In fact it scares me so much my response is always "nobody really knows". The other children with TTD that I am in contact with are all younger than him, and because this disorder is so rare, I have only been able to find 30 other families in Australia, 56 world-wide.

In 2003 we travelled to America to meet up with scientists and doctors from NIH and MAYO Clinic and UCSF Hospitals which helped change the quality of his life. Although not cured, his quality of life has greatly changed.

Sammy-Joe is my pride and joy, my heart and soul, and my whole reason for living. He is truly a miracle child and a survivor, an inspiration to his family and friends. His brother Christian adores him, and he is the apple of his Dad's eye. We love both our children and have taught them to be very proud and stand tall, despite all the challenges that life brings us.

Christian is an equally amazing young brother who cares for his older brother, but now has had to take on the big brother role. Christian finds life challenging when having to explain that his older brother is really like a younger brother, because Sammy-Joe cannot do the regular things that other nineteen year olds can. Christian also struggles to understand and cope with the grief that he feels when he has thoughts of losing his brother through the illness called Trichothiodystrophy.

Sammy-Joe and Christian constantly amaze us with their incredible love and happiness for being together, and for their sheer love of life.

Like all parents, we want everything for both our children and thinking ahead about what the future may, or may not hold, makes us strengthen our determination to see that our children have every opportunity and experience that they both deserve. Sammy-Joe's diagnosis has forced us to re-evaluate our entire lives and the way we live. We surround ourselves with family and friends who understand and are sensitive to our situation. We decided as a family that whilst Sammy-Joe's diagnosis is devastating and we have no control over it and the final outcome, we do have control over the way we manage our situation and the way we choose to give Sammy-Joe a quality of life that best suits him. The simple things in life really do mean much more, and spending quality time with our sons means so much more to us. We live day by day and enjoy every moment with our precious boys.

I'd like to tell you all that as long as we are blessed with Sammy-Joe and Christian we will have all that we need. Everything else seems so unimportant. Sammy-Joe will always touch hearts, and even change lives with his smile. Christian will always be a kind hearted gentle soul that has been touched by having a brother with a chronic illness. My family means the world to me. I will go to any lengths to keep them safe, happy, protected and loved. I just want us to be a happy family. Having Sammy-Joe and Christian has taught me many things; it's taught me patience, tolerance strength and unconditional love.

Having organisations like Carers Links North, Young Carers Victoria, Melbourne City Mission, and everyone that have so generously stretched out a hand, has been life changing. It's shown me that people are out there when you call out for help. Without these organisations life would have been very very hard.

The Pavilion that is being built by Delfin and Naturform will be a safe area for Sammy-Joe to play in with his brother. It is something that will change all of our lives. We are all grateful and believe that we have been blessed with a Miracle.

**Maria Liistro**

# THE LIISTRO FAMILY STORY

## RESPONSE FOR MARIA

### For Maria from Norma

Thank you for sharing your thoughts with me. As a mum I was very moved by your letter, your dreams for your family and by the strengths and skills that you have learned as part of your "mum" role. I was impressed by your generosity for the service providers involved in your lives. It cannot be easy to open your home to so many and still remain so positive in your outlook. In my future work with families I will remember your words "we have been blessed with a miracle" and will keep in mind that miracles can happen if we remain open and keep looking.

### Joe's Story

It has been difficult accepting that my eldest son has a condition so rare that the sun could kill him. My other boy Christian has been my strength as well, watching them both grow as individuals has been something that a father handles silently, with pride or sadness, in my case I have to deal with both. I have been going through depression and a lot of it has been grief over not accepting what my son has to go through, also watching Christian grow and be basically like an only child because Sammy-Joe cannot keep up with his younger brother that has now taken on the older brother role.

My silent wishes have been that both my sons have a 'normal life'. Sometimes I find it difficult to express what I am truly feeling. Being a father, a husband, a carer has helped me to grow in so many ways. It hasn't been an easy task, but it has been a journey that I would do all over again if I had to. Despite the grief that I have been feeling I cannot imagine my life without my family.

I admire my wife for all that she has tried to achieve and I am very proud of both my boys. There is no other place I would rather be than with them and growing old beside them.

We have been faced with so many challenges and also so many disappointments. We have experienced hardship and pain and also so many little joys. Our recent joy and wish has been knowing that there are organisations out there such as Young Carers Victoria, Melbourne City Mission, CarerLinks North, Very Special Kids, The Lions Club and now Delfin and Naturform. These organisations have so generously helped us in many ways.

Having these organisations step in has transformed all the despair into hope. The

Young Carers group has helped my son Christian deal with so many challenges about his brother. It has helped him to feel important as a young carer. As his father I have been watching the change in Christian. He has changed and matured into a nice young man. He has faced being the sibling of a child with a disability head on and with strength. He has taught me to be strong. To watch a young brother protect, care and love his brother with a disability and not see him as any different, has ~~helped~~ <sup>inspired</sup> me to accept. Apart from my wife, Christian has been my mentor.

I love both my boys and all I want is for them both to have a comfortable and happy life. Delfin and Naturform have helped us to achieve our goal. They have joined forces to build a pavilion attached to our house which will be solar protected for Sammy-Joe. The pavilion will change us as a family. We can socialise within a safe environment for Sammy-Joe and spend more time doing things as a family and Sammy-Joe and Christian will be able to spend quality time together.

We are grateful to everyone that has helped us to achieve our dreams.

Thank you  
Joe Liistro

## RESPONSE FOR JOE

### For Joe from Norma

I was very moved by the strength of your love and concern for your family. Despite your own anguish you can find room in your heart to be a loving father and husband. You have a real strength of character.

While I was reading your letter I was reminded about how fathers are often on the periphery of their children's care. Mothers are at home and are the primary care givers when service providers come into the home. So I was reminded that I must make a special effort in future to include dad in discussions and decisions about family matters.

# THE LIISTRO FAMILY STORY

## Christian's Story – 15

My name is Christian and my brother's name is Sammy-Joe.

Sammy-Joe has an illness, a disability and sometimes I am the only one that understands him. I don't like people to tease him, or to say things about him. I try to protect him from that. I have now become the big brother. For only 5 years I was the younger brother and I looked to my brother for help.

Sometimes I would wonder why he couldn't talk, or do the things that others could do.

I remember seeing him in hospital a lot of the time. It upsets me to see this and I couldn't understand why he was always so sick. When he turned 13, I remember my parents crying because they were told that Sammy-Joe could die. I hated hearing that and I didn't believe it either because I knew that Sammy-Joe was strong and tough; he sometimes wrestles me to the ground.

I know that Sammy-Joe can never do the things that I can, but sometimes I wish I could just stay home from school and look after him. I take care of him sometimes during the night when my parents are too tired, or don't hear him wake up. I know that I have to, I feel that I have to.

My favourite thing to do is to play basketball, it's my favourite sport. I like it when Sammy-Joe can watch me play outside in the dark. Sometimes we would play on the trampoline together at night, now it's too hard because Sammy-Joe is like a four year old with his mind. Sometimes he throws tantrums and sometimes he is too sick to do anything. It's been hard, but I like being with my family. Having the structure is going to be fun because Sammy-Joe won't be so frustrated, there will be more room to play and he can spend some time with me in there.

Marti has come to be my friend and he has made sure that I have had some things for me because sometimes I have missed out on things because my parents couldn't afford things. It's been good having other people that understand my situation.

**Christian**

## RESPONSE FOR CHRISTIAN

**For Christian from Norma**

WOW! Christian I was so impressed by the love that you have for your brother and how you became strong and supportive when you could so easily have stayed the younger brother (who always looks to other members of the family for protection and support).

I think that Sammy-Joe is very lucky to have someone who understands him and protects him as you do. Your letter has taught me to never underestimate the strength and resilience of younger brothers and how they can be a champion for other family members.

## ARE YOU A CARER?

Looking after yourself is important!

Come and learn ways to care for yourself

**When: Tuesday, 29th July**  
**5pm til 6pm**

**Where: Craigieburn Health Service**

350 Craigieburn Road West

Craigieburn, 3064

(Next to McDonald's)

**Who:** Family, friends or anyone who cares for someone who is aged, Disabled or has a physical or mental illness

**RSVP: 22<sup>nd</sup> July 2008**

Cathy Lucci  
8338 3056

Kristy Dodwell  
8371 9800



# The Friends of Sammy-Joes Newsletter



SHOW YOUR SUPPORT FOR THE FRIENDS OF SAMMY-JOE FOUNDATION BY PURCHASING THESE ITEMS .

We are selling wristbands for 2.00 dollars each and pens at 2.00 dollars each , please support us by purchasing these items , also we have shaker tins , if you think you can help with selling these or keeping a tin at your local business , please call Maria on 0407 558 151 and we will get these items to you .

**IT IS IMPORTANT TO RAISE AWARENESS ON ALL GENETIC CONDITIONS , THIS CAN LEAD TO EARLY DIAGNOSES AND ALSO CAN EVEN SAVE LIVES , IT CAN HELP THE PERSON WITH THE CONDITION TO NOT FEEL ALONE  
HELP US ON OUR CAMPAIGN TO HELP RAISE AWARENESS WE ARE ALWAYS OPEN TO SURGESTIONS**



Lets focus on why we are here and where our intentions need to be, the focus of our Foundation is to help the struggling families that experience so much hardship, pain and sorrow dealing with the everyday challenges of these illnesses, lets focus on the children and young adults that have to endure that pain without choice, lets make a difference to their lives, lets focus.

**Maria Liistro**



**Newsletter Written by Maria Liistro**

**Produced and Designed by John Willis of J D;S Computer Solutions**