The Noonan Syndrome Support Group, Inc.

THE NOONAN CONNECTION Winter 2003

HELLO FROM THE PRESIDENT

At times life gets in the way of remembering to be grateful for our many blessings. Remembering to say thank you to the people that make this family (group) a success . Including those people behind the scenes who give of their gifts and talents without adequate recognition.

People like Michael .T. Blair, an accountant in Carroll county, MD. Whom I contacted, based on the recommendation of a stranger.

After explaining who we were and what our mission was Michael never hesitated, he and his staff continue to provide this family (group) with dedicated care 7 years later.

As dose Rachel A. Israel, Esq., LLM Of Murphy, Hesse, Toomey & Lehane, LLP, one of our own members. While talking to Rachel several years ago I asked what was involved in getting the groups name and logo Trade Marked. We are indebted to Rachel A. Israel, Esq., LLM, Of Murphy, Hesse, Toomey & Lehane, LLP, for everything she has done to protect the identity of the family (group).

Take some time this holiday season with family and friends to celebrate and relax as you count your blessings. I know that Noonan syndrome dose not take a break. To those who live with it each and every day, its effect at times are relentless.

The Noonan Syndrome Support Group, Inc. has made a commitment to partner with other Advocacy Organization in what would be the first Bio-Repository (a DNA bank) that is owned and managed by the persons/groups it directly affects. As such the Bio-Repository is set up as a Not for Profit, with strict guidelines for membership.

Our next conference will be July 16, 17 and 18th, 2004 in Towson , MD. Mark your calendars now. Registration forms will be mailed in January.

Individuals and organizations as full partners with researchers will ensure benefits outweigh risks, and accelerate the translation of research to treatments. The Bio-Bank will provide a Strong Catalyst for Accelerated, Coordinated and Ethical Research

Here are the benefits of partnering with other Advocacy Organizations rather than starting our own or going with an established Bio-Repository (a DNA bank):

- Less expensive, generally
- Power of lay organizations together
- Cross disease research
- Support, mentoring for one another

This is exciting news for our family (group), and now more than ever we will need your continued commitment and support.

Wanda H. Robinson
President

THE NOONAN SYNDROME SUPPORT GROUP, Inc.
A Non-Profit Organization
We reach around the world!
Founder and President: Wanda Robinson
Vice President: Dave Robinson
Secretary: Pamela Hauck
Medical Advisor: Dr. J. Noonan

The Noonan Syndrome Support Group , Inc. was founded in June 1996, by Wanda Robinson.

We offer information and support to those whose lives are touched by Noonan syndrome. The group is self funded. Contributions are gratefully accepted and will help the next family to receive information about Noonan syndrome.

You can reach us at:
E-mail: **wandar@bellatlantic.net**
Or:
info@noonansyndrome.org
Web page:
http://www.noonansyndrome.org
Mail:
TNSSG, Inc. PO Box 145
Upperco, MD 21155

Telecommunication service is Funded by the Minnesota Chapter of TNSSG, Inc.

1-888-686-2224 within the United States or

1-410-374-5245 outside of the United States

Did you know these characteristics are common in Noonan syndrome?

Clinical Characteristics
Short stature (2 SD below mean)
Triangular shape of face
Prominent brow
Hypertelorism
Epicanthus
Antimongoloid palpebral slant
Ptosis
Depressed nasal bridge
Broad apex nasi
Low-set and/or malformed ears
High-arched palate
Normal karyotype

Neck
Short
Webbing
Low hairline

Chest
Shield-like
Wide-spaced nipples
Pectus exacavatum

Cardiac Abnormalities
Pulmonic stenosis (PS)
PS and ventricular septal defect
Atrial septal defect (ASD)
ASD with anomalous pulmonary venous return
Endocardial cushion defect (ECD)
ECD + patent ductus arteriosus and mitral insufficiency
Both PS and ASD
Patent ductus arteriosus (PDA)
Undiagnosed heart disease

Extremities
Cubitus valgus
Gracile fingers
Short stubby fingers
Lymphedema
Dystrophic nails
Shortened fourth metacarpal(s)
Clinodactyly of fifth finger(s)
Palmar simian crease
Undescended testes
Delayed puberty
Skeletal retardation

Cognitive Development
Learning disability
Cognitive disability

WE NEED YOUR HELP. IF YOU LIVE OUTSIDE THE USA?

Would you be willing to photo copy the Noonan Connection and mail it to other people in your country? It has become to expensive to mail each edition of The Noonan Connection out of country.

An edited edition of The Noonan Connection is available online. 28 people in the UK will receive this edition thanks to the efforts of **Michelle Ellis**, we would also like to thank (Simon Bland of) East Surrey College, Redhill, Surrey, U.K for kindly photocopying this newsletter.

Contact: wandar@bellatlantic.net if you can help

FROM THE HEART

Call it Holland, China, …

I first joined this group when my son Rowan was five months old and I had just been told he has NS. When I first spoke with Wanda, she, and this group as a whole, were the life preserver I needed to keep afloat during this tumultuous time in my life. I asked questions and looked through every article and picture available on the Website that would prove to me that my son did not have this or any other syndrome. I was hoping to hear "Oh no, he doesn't have NS, you don't need to be in this group." I searched for hours that turned to days and weeks.

My search for those answers was in vain, but what I did find in all of you is an incredible source of support whenever I need it and in those first months I really needed it. I was lost in a place I never expected to find myself and I didn't want to be there.

Since the day my son was born I felt this deep bond with him, deeper than I remember ever feeling before. Then he was

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MORE THE HEART

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given this label and suddenly I looked down upon him and I felt I did not know who he was any longer. My world came crashing down around me and all rational thought and emotion seemed to be gone. Those first weeks were the hardest I ever had to deal with. I didn't know when I was coming or going. I didn't know how to feel, except guilty; incredibly guilty. I was in a place I didn't want to be. Call it Holland, China, Hell, it didn't matter, I didn't want it and wasn't about to accept it and that was a tough space to be in.

Then, thankfully, after a few weeks it dawned on me. My bond with Rowan was so deep and so pure because of who he is and who he had been from the day he was conceived. His NS was a part of him as much as any other part of him and all of him is who I fell in love with. It was such a relief to realize that the only thing that was wrong with Rowan at that time in his life was me. He was the same incredible child now that he was the first day he came into my life, I was the one who had changed. From that moment on I stopped trying to turn Rowan into someone that he was not and put all of my efforts into making sure I was able to help Rowan to be everything he is meant to be.

I am in a place in our lives now that, for the most part, I accept things as they are. I have learned to take things as they come and not try hard not to forecast into the future what may be. I realize that Rowan has more to deal with in his life than many, and less to deal with than a great number of others. That is not to say that I don't have my moments. I have plenty of moments where fear takes over, but they are only moments and I can live with that most days. My vision is more clear now. I didn't plan this "journey to Holland" but I am now willing to take it and go wherever else it is I need to go to make this life a great one for Rowan. I am no longer gripped in so much pain and fear that I cannot breathe. Now the only time I find myself holding my breath is when one of my precious children, in all their glory, takes my breath away.

I have more appreciation now for the simple things, the miracles that give light to my days; the belly laughs, the ever so soft kisses that only a toddler can give, the way my baby smells and feels as his soft cheeks are pressed up against mine, the way his breath touches me as tucks he sweet little face up into the curve of my neck; the way he runs to his sisters and hugs them around the legs with all the delight he can muster. Those are the things that matter. All the smiles and laughter that Rowan has brought to our family has by far outweighed the heart ache of learning that he is not "perfect". And "perfect" has taken on a whole new meaning in my life.

But, I also realize, that I had to go through the darkness to reach the light. I had to know this almost unbearable pain, to realize how incredibly lucky I am to have this beautiful child touch my life each and every day.

So, I guess I am just trying to share this a small part of my heart and soul to those who might be just now going through the initial steps of this journey. We all have our individual stories to tell, but as parents I think we all meet on the same page when it comes to the love we feel for our children and the emotions that go with that.

Kim Knight
Mom to Rowan 22 months w/NS, and daughters Seanna 8 and Gaelen 6 1/2 w/no NS, wife to Jim

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Fear of the Unknown…

My name is Amy Roche and my son is Edward. I know our story is probably just like yours, but I want to share it anyway.

On a Thursday morning in February, Edward came into the world. He came into the world struggling to breathe and to live. He was a few minutes old and I knew he was a fighter. I just didn't understand what he was fighting with. Like all new moms, I couldn't wait to hold him, smell him, count his fingers and toes. I couldn't wait to snuggle him.

Something is wrong, though. Why won't anyone tell me? I barely get sight of him before he is taken away. For the next 5 days I watch as he is poked so many times his feet are black from the bruising and he flinches when the are touched. I watch as he struggles to breathe, his little chest working so hard. What? You say he should be at 40-60 heartbeats per minute and he is at 190? I watch as he cries, screams even because I know he is hungry and the Dr's will not let him eat. I ride the rollercoaster of emotion as doctor after doctor tells me he is just in prolonged distress, he will be better soon. I watch as the Transport team comes and loads him into the Transport case. He needs to be at a more adequately equipped facility. I watch as they take my son away. My new son. I am supposed to be taking him home today. I wonder what I did wrong. I watch as he is yet again loaded in the Transport case a few days later, we are moving to the third hospital. The Doctors tell me he may die. He needs to move now. Get here as fast as you can.

There are all these words… words I do not know, I have never heard before. Pulmonary what? Noonan who? Hole in what part of the heart? Severe Regurgitation? How can he throw up when you are not feeding him (I know better now)? Surgery tonight? What do you mean I can't ride with him? Can't I hold him once before you take him? Just in case…

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MORE THE HEART

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Thankfully, one Neonatologist speaks up. **Give this woman her baby, he says.**

Finally, my moment...as he lays in my arms, he stares at me. I am overcome and I cannot stop crying. Please God, I just met him don't take him from me. I look at him and he is so peaceful, I think, there is nothing wrong with him, nothing at all. But they take him from me...again.

Another hospital. Another waiting room. Only this one is different. In this waiting room, I sit and I steel myself for the death of my son. My head is throbbing. My heart is aching. Here they come. Be strong, I tell myself. He will not die tonight, she says. I wonder, is this supposed to be comforting? What about tomorrow or next week? He has Noonan Syndrome; he has multiple heart defects she says. Be cautiously optimistic she says, he will pull through this.

Fear. I am crippled by fear. For my son, for what his life will be like. I ask the doctor about Noonan Syndrome. She paints a bleak picture. She cannot answer all my questions. Who can I talk to? Who knows? Who can help me understand this? She hands me a pamphlet, it reads "Understanding Noonan Syndrome" from the Noonan Syndrome Support Group.

I go to the website. I sign up and I post a message. Within 24 hours, I have heard from more than 30 people. People who know my story before I tell it, who support me who tell me not to be afraid. People who offer suggestions and advise. People who understand. People who made the fear of this unknown disappear. For that, my sons life will be all the better and I am forever grateful.

Amy _____

"This past six months is a blur"

I said to my mother when she asked if I remembered a certain event. "I think I was in a fog, moving in auto-pilot", I continued. Six months later it is becoming clearer to me. I am no longer facing each day with uncertainty and the lines on my forehead don't appear to be as deep. What follows is the story of a mother's journey – from conception through infancy of her new son. It is a story of acceptance….

After years of trying to become pregnant with a second child, it happened somewhat unexpectedly. No doctors, no pills, no shots, no laboratory, just the regular way, I was finally pregnant. We were living overseas at the time and I found a French doctor who was recommended by some other Americans. At my 8 week visit she told me that she was concerned that our fetus "may" have Down Syndrome. She based this concern on the excess skin on the back of the fetus' neck which has been associated with Down Syndrome and other genetic problems. Devastated, I went home to tell my husband and frantically do my own research. I called a friend in the U.S. who is a Family Practitioner who told me that many physicians in the States don't even perform this test anymore due to all of the false positives. I relaxed a bit and waited the six weeks for the amniocentesis. I traveled two hours to a new Dr. at an American-accredited hospital for the amnio. The results showed a normal male fetus. Finally, we celebrate the pregnancy!

My eight year old son and I traveled back to the States to visit my mother and to wait for the baby to arrive. My husband stayed overseas until we get closer to the due date. The pregnancy was going fine and my son was looking forward to meeting his new brother. I found yet another OB/GYN and at 34 weeks gestation, she is a bit alarmed at the size of the baby and the size of his left kidney. She referred me to a high-risk OB. He measured the baby's kidney and asked me to come back in three days. I went back and the baby's kidney was measured again. This time, there was some concern that the massive kidney was crowding the abdomen because the heart seemed to have moved into the right side of the chest. He wanted to perform the C-section that afternoon. "OK, but this is not working into my plan. My husband isn't even here and it is five weeks too soon," I said sort-of to him but mostly to myself.

Regardless, the baby was delivered that night. They quickly showed him to me and whisked him off to the special care nursery. Not really the birth experience a woman dreams about! The baby, though, was beautiful. Although he was frowning and not too happy to have been snatched from the womb, he looked like a perfect, sweet angel to me. He had loads of black hair and nice eyes. The next morning, though, I learned that he was far from perfect. The Neonatologist came to my room with a list, I'm not joking, he had a list of all of the things that were wrong with my gorgeous baby. It went something like this… his platelet count is extremely low and we need to give him a transfusion right away, his kidney will need to be examined by a Pediatric Urologist, a heart murmur has been detected and he'll need to see a Cardiologist, his testicles are undescended, his white blood cells are very high, his eyes are a bit wide, his nasal bridge is flat, and his ears are low and rotated and with all of this we will refer him for a Genetics consult. My head was spinning and I was totally speechless. It was as if I was watching a movie about somebody else's baby. This was the most difficult time of my entire experience, just hearing it!

Several of my friends came by to visit me. They didn't know what to say to me. Do you say "congratulations" when something is so wrong? One friend asked if I wanted him to walk down to the nursery with me to see the baby. I told him, "No, I'm afraid of getting attached to him." I changed my mind a few minutes

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MORE FROM THE HEART

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later and went down and finally held my baby while sobbing. "Why has this happened to my sweet, innocent baby?" I asked myself over and over again.

Only twenty-four hours after his birth, my baby was being transferred over to the NICU at Children's which would become our home for the next three weeks. By now, my husband had been called and was on the way. Thank god that I would no longer have to bear this "mourning" alone. I call it mourning because that is the only way I can describe the feeling. I was mourning the healthy child that I had dreamed about.

Our sweet baby endured many blood tests, EKG's, echos, x-rays, renal scans, and under sedation had his kidney drained and a nephostomy tube placed. He was about one week old when the Geneticist came to speak with us and the term Noonan Syndrome came up. She gave us information on Noonan's and we poured over it. We went to the medical library where we devoured even more information. I was desperate to talk to someone who knew this condition on a personal level. I found Wanda Robinson's name on a pamphlet and called her from the hospital. She told me her experience, answered some of my questions and made me feel like I was not alone.

We left the NICU when Idrees (our son's name) was three weeks old, we had a more complete picture of his medical status and were armoured with the information to help us through. My husband had to go back to work overseas and I sure wasn't going to take this medically fragile child out of the U.S. so my two sons and I stayed with my parents for the winter. The first few months were filled with doctor's visits, sleepless nights and worry, lots of worry! We made it through the first surgery (for the obstructed kidney). I took him to the hospital by myself and stayed there for the two nights. Then there was the Cardiac Catheterization and later we learned that the kidney surgery hadn't worked. We went back for another nephrostomy tube (these come out of the body and drain into a diaper) and the doctor who placed it knicked a blood vessel. I woke up the next morning to find blood all over my son's nightgown. Back to the hospital where they tried for one and a half hours to get an IV in and ended up having to go for a pic-line. My point here is that it was a heck of a roller coaster ride. One minute I'm nuzzling this sweet baby, nursing him and loving motherhood, the next I'm rushing in my mini-van to the hospital with my bleeding or feverish baby.

Over the next few months though, things began to calm. There were less frequent doctor's visits and most importantly, I had accepted my son's medical condition. It had become a part of life and I became much more confident in my ability to care for him. I moved to my new house with the two boys. My husband came home for the summer and fell in love with his new son and we finally got to be a family. We sailed through his cardiac surgery to repair his AV canal defect and pulmonary stenosis as if we were seasoned veterans. Now we relish the little "typical baby" things, like when he started waving bye-bye, said Mama for the first time, and started cruising around the furniture. A year ago, I couldn't even imagine that I could endure the things that we've been through in the past year. I know now that I am a stronger person. I have accepted the ultimate challenge of raising and loving this special child.

I no longer ask myself why this has happened to my son. It doesn't really matter. I am too busy chasing him (he's size of a typical 5 month old, just to give you a mental image) while he is running through my house giggling and showing the two tiny teeth that have sprouted from his lower gums.

My older son has asked several times if Idrees would be this cute if he didn't have Noonan Syndrome. "I don't know but he'd be different, I suppose," I tell him. My son replies, "I like him just the way he is". "Yeah, me too!"

Theresa Mahmood

Child Life was there…

Hello, I am so happy to hear that Child Life was there to help you and Nathaniel. You know, actually it is not a bad request to ask for Child Life again. If you know in advance ask your doctor to contact Child Life ahead of time. If it is spur of the moment, it never hurts to ask then also. If they are not there, you can always ask someone else to do the holding (I truly recommend comfort holding techniques rather than holding him down) and you can try to entertain him. Although I know that that may be harder to do, he may more likely seek comfort from you and that is ok.

You can always get a fun book that he likes a character to and give it to him at the time of the appt. so that it is something new and interesting to look at, it may help distract him more. You could also suggest to the doctor or lab to put together a toy distraction back pack, that they use just for the lab draws and that is it.

Let me know if you need some suggestions as to what to put in it, the Child life staff you worked with may have suggestions too. Also I always encourage comfort holding positions too. Have the Child Life staff show you a few to help with his blood draws, it really makes a difference. I am not sure I recognize the abbreviations for CFC. I am sure it is obvious but I cant think. What is CFC? Hope to talk with you soon.

Heather Bazzocco

To all our family and friends…

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MORE FROM THE HEART

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From Heather and Aren Bazzocco

UPDATE - October 23 -- We lost our little girl. Payton passed quietly in her mommy's arms very early this morning. There are no words that can explain the emptiness that we feel. Services will be held at East Lawn Sierra Hills on Greenback Lane, Thursday October 30th at 2pm. We welcome the attendance of all who touched our lives during this time, and likewise, those of you who were touched by our precious girl. We have established The Payton Hadley Bazzocco Foundation, which will benefit children with Noonan's Syndrome. If you so desire, contributions can be sent to the Sacramento Regional Foundation with a note on the check stating that its for the benefit of The Payton Hadley Bazzocco Foundation. Donations should be sent to:

Sacramento Regional Foundation
555 Capitol Mall, Suite 550
Sacramento, CA 95814

HYPOTHYROIDISM CAN CAUSE THE HAIR TO BE VERY SPARSE AND EVEN TO FALL OUT.

ONE YOUNG LADIES JOURNEY.

The greatest cosmetic issue related to Noonan Syndrome that my daughter, Courtney (age 9 1/2) has had to deal with is sparse, slow growing hair. It was the hair issue that originally led me to the listserve when she was just 5 years old and getting ready to enter kindergarten. She was still practically bald.

Her hair looked like that of an infant, still coming in patchy all over and very short. I was extremely worried about teasing, because at the time she didn't see herself as any different from the other children. She knew she had "short hair" but didn't realize that it was so "different." One little girl in her preschool class once told her, "you can't play with me because you don't have any hair." She came home saying, "Mommy she said I don't have any hair and I have hair." I reassured her that, of course she had hair, it was just short, and, thankfully, this little girl ended up leaving the preschool and the other children were great.

Courtney continued on to kindergarten and was always treated well by the other kids. She seems to have a self-assuredness that other children are drawn to, and has actually been quite "popular" with the other children. I continued with the hair concerns and brought up the issue with several doctors. Nobody seemed to know what to do. A pediatric dermatologist gave me permission to use Minoxidil (Rogaine) for her at about age 7. This helped some, but I wasn't comfortable using it long term due to possible side effects, and the results were far from dramatic.

Finally, at age 8 Courtney was diagnosed with **hypothyroidism**. This can cause the hair to be very sparse and even to fall out. I don't believe this was the cause of her slow growing hair when she was younger because she had had thyroid testing done when she was approximately 3 or 4 years old and it had come back normal. The doctors believed she may have had **low thyroid** for about a year when she was diagnosed, and when she was diagnosed her thyroid levels were basically depleted. It's amazing that she was functioning as well as she was, because this also cause extreme fatigue, constipation, bloating and weight gain.

Courtney has now been on thyroid hormone for about 1 1/2 years. She was put on growth hormone about 7 months ago due to a deficiency also. Both seem to be contributing to better hair growth, but the progress is slow. I just took Courtney for a haircut yesterday. My hairdresser put in some layers and evened her out all over and styled it for her. Courtney was strutting around bobbing her head afterwards, acting like a real drama queen. She was delighted with the results. Courtney's hair is still short, but has filled in dramatically. With short hair cuts in style now, her hair finally looks fairly "normal." I know she would still love to have long, flowing hair like her younger sisters, and I hope someday she will. For now, she and I are both very happy with the progress she's made.

LOW THYROID - HYPOTHYROIDISM .. THE MOST COMMON CAUSE OF LOW THYROID PRODUCTION IS AN AUTOIMMUNE DISEASE CALLED HASHIMOTO'S THYROIDITIS IN WHICH YOUR LYMPHOCYTES MAKE ANTIBODIES WHICH SLOWLY AND GRADUALLY DISABLE THE HORMONE-PRODUCING CELLS IN YOUR THYROID GLAND.

My advice to any parent of a child with NS is to treat them as normally as possible. Courtney doesn't focus on her differences and has more confidence than most kids I know. I have taught her that beauty comes from within and she's beautiful both inside and out. She's the greatest blessing and teacher that I have ever had the privilege of knowing. I thank God for her everyday.

Karen Khal (Mom to Courtney 9 with NS and born with hydrops, hydronephrosis, PS, ASD, malrotation, now hypothyroid, growth hormone deficient and taking growth hormone, Kathleen 7, Janie 6 and wife to Sam) Michigan, USA

NOTE— LOW THYROID IS NOT UNCOMMON IN PEOPLE WITH NOONAN SYNDROME. The most important test in making a certain diagnosis of this condition is your TSH blood level. The level of the thyroid hormones (T4 and T3) may also be checked, but these tests are less sensitive than the TSH level in making a decision about the diagnosis of primary hypothyroidism or the dose of medication that you might require.

Thank you to the following people, companies and foundations for their continued support. They are making a difference.
Because of them we will continue to tell others about Noonan syndrome! June 2003 –December 10, 2003

♥ **MEMORIAL GIFTS**

William N. Graff
Karen and Craig Schottenstein
Joy Minns
Louisa Rivers Robb

Lee Oscar Walker
Kathy Grace

Danny Thompson
Rene' Sewell

Elizabeth Newman Chalis
John & Erin Gallagher
Bert Neufeld
Ellen Ayre

Catherine Ann Trimboli
William and Helen Trimboli

♥ **THE CHRISTMAS GIFT**
Jane and Leonard Sherwood and Family

♥ **TORCHBEARER**
Patrick and Connie Larkin

♥ **CHAMPION**
William and Linda Kwochko
Janis Ryan
Linda Johnson
Harriet Kessler (Directline)
Martin Chappell
William Hudlow - In Honor of Matthew Chapman
Dr. J. Noonan
James and Lyn Wessels
Teresa Sherwood
Veronica Miller
Peggy Edwards - In Honor of Nicholas Edwards Birthday
Michael and Robin Goldberg
Theresa Capinski
Joel and Elaine Nixon - In honor of Grace E. Mayr

♥ **GENERAL CONTRIBUTIONS**
Wayne and Hillery Clarke
Mike and Laura Finney
Linda and Stephen Bruce - In honor of Michael Bruce
Brenda and Melvin Schrager
Susan and Randall George
Clay and Danelle Petero
Sandra Nolen - In honor of Holly Gordons Birthday
Mr. Crouch (BK)
Inna Snitkovskaya
Caryn and Philip Winters
Millard Bass
Patricia Emons
Donna Ryczek O'Toole
Susan Gold
Lyla dD'Ann Harris Blevin
Bryan and Lisa Clapper
Robert and Sistine Emons
Larry and Louis Davis
Paul and Staci Auer
Lloyd and Arlene Peterson
John and Doris Floyd
Terrence and Maureen Thompson
Thomas and Anne King
Louis and Lillian Levy - In honor of Mr. and Mrs. Murray Goldberg
Robin Richards-Szabo
Charles and Pamela Breeden
Thomas and Ann Marie Pum-Swoboda

♥ **FUNDRAISING EVENTS**
February Valentine Event
Minnesota Chapter

Neighborhood Yard Sale
Lisa Merchant and Friends

♥ **UNITED WAY GIVING**
United Way of North Eastern NY
State Employees Federated Appeal
United Way of Tri State
United Way Merrimack Valley Inc
United Way Northeast Florida
United Way of Kitsap County
United Way of NY

♥ **COMPANY MATCHES**
SBC Matching Grant
Glaxo Smith Kline Foundation

AN ADULT IN SOUTH AFRICA

An adult with Noonan syndrome talks about his journey...

My name is Drikus Louw and I'm living on the other side of the world in sunny South Africa. I was diagnosed with NS when aged between 12-13. When I read your web page, certain things just made much more sense to me. Unfortunately I have limited access to a computer, but I have a moment to share my story.

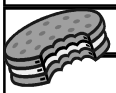
I was born with most of the common "defects" as mentioned, but decided not to give up. Fortunately most of the problems was minor and I'm 34 now, living a full life. I used to work for a shop fitting company as an artisan, but ventured into the horse business as I loved to ride. I have done 100 mile endurances and ended up in the US working with Saddlebreds at one of the best trainers in the world. From there I went to Newmarket in England, working with Racing Arabians for a well known trainer. In the end after 23 years of riding I decided to quit with horses all together and at this stage I'm studying further and hope to finish my degree in 2005.

Wanda, my heart broke when I read about these kids, suffering in the same way I did, but the more I look at their circumstances, the more I realize how blessed I am. Each of these kids are special and I just want to thank you and your team for such diligent work. If I look back on my life, I really have to give my mom and dad gold medals for raising me. They have done what they could with the very little they had. There was no true answers for my condition and I guess my mom had to take the "knock" because with heart defect and all, I played with the other so-called hyperactive kids until they were tired... and then I'm still going strong, almost like a Duracell. They have taught me to be myself and not to let anything stand in my way to reach my dreams. Yes, deep down inside there were times that I hated myself for who and what I was, but that was changed some years ago when I gave my heart to the Lord Jesus. He is still working in me and the "job" will be truly done when I go "home" to be with Him.

Keep going on with what you and your team are doing, keep encouraging the poor parents that are searching for answers and cures. Stand up for the kids that don't always understand themselves and teach them that there's a wonderful life out there, even with the setbacks of NS. It was nice talking to you, a total stranger, but joined by the same concern. Please encourage people the way you do and if you want to you can write me back. I'm praying for you and your team, as well as those that have to deal with the same problem because there's an answer to everything with the Lord Jesus. Stay well and don't give up, even when things look dark around you.

Love in Christ,

Drikus (shortman)



THE JOURNEY CONTINUES

"If you've ever wanted to crawl in the closet with an Oreo..." by Martha Kate Downey, mother to Kate, age 21 with Noonan Syndrome and autism

FEAR OF THE FUTURE

When Kate was a child, I thought, "As soon as she gets a little older..." I looked toward the future as a cure all for difficult stages she seemed to be having. Actually, I was looking toward the future for difficult stages I was having! It helped to some extent, except that as soon as one stage passed, another began. She rarely gave me time to catch my breath. What her regime for me did, however, was teach me how to be a distant runner. She taught me how to pace myself, how to find snatches of respite here and there, and how not to assume that she would remain the same day to day (making my mastery of each stage feel so imperative). So now, with Kate at age 21, I still sometimes look toward her future, and ultimately, mine, too, with a degree of trepidation. But rather than overwhelming fear that her father and I won't know what to do, I now have the growing assurance that we will be able to survive the future. I positively, know for certain, that I will continue to grow in my strength, knowledge and compassion. I know we will continue to meet amazing people who will weave through our lives, leaving a pattern that makes us stronger, braver and a little wiser. I know that while Kate's journey is important, so is mine. I know her life challenges will continue to be my difficult "Harvard" course in character development. Not her character development, but rather my own. Kate has her own struggles, but moves through her life in an assured manner because of her definite knowledge that she can survive. She doesn't fear her future as much as her father and I fear it, because she has the wisdom to know, she can only do today..today.

We all will continue to be diligent with our children, but we must be diligent with ourselves, too. We must learn the real lessons they teach: that hope is crucial, it turns a stumbling block into a stepping stone; that patience is hard to learn and only achieved by letting control go; and that all children cause heartache and concern, but that we parents must learn to trust them.

As the years pass, I find that my expectation of the future is now less fearful and more curious, it is less anxiety and control ridden and is more willing to let Kate be who Kate is. It is less "I have to be the best mother" and more..."This is me, this is my life. I can choose to accept it and yes, even love it, or I can choose to fight it and so, despise it." Which do I choose? Well, most days I

(Continued on page 9)

(Continued from page 8)
choose to accept it.....it takes much less energy ;-) and gives Kate a better role model for handling personal challenges herself.

Our children are dependent on us for their care, but NOT dependent on us for their life support. They draw their own breath, let us remember to draw our own, too. It isn't selfish, but rather sustaining, energizing and life fulfilling rather than life fearfulling.

Love to you all.
Martha Kate Downey

author of: If you've ever wanted to crawl in the closet with an OREO
TAP DANCING in the night
The People in a Girl's Life (co-authored with daughter Kate Noelle Downey)
What Do I Do About Hitting?!visit her or drop her a line at

www.mkdowney.com

Antibiotics cause Allergic Reaction

We have luckily never had a very dangerous experience, but Livia is allergic to penicillin's (the whole group) and also the entire group of cephalosporin's. Liv was on antibiotics approx. twice a month for ear infections and sinus infections from about 8 months to 2 years of age. The first drug was augmentin. She woke up in the middle of the night and I thought she had been bitten to death by a mosquito. I had just never seen hives before. Also, it was on the eleventh day (so she had her full ten day course with no problems and then developed them the day after treatment stopped). She also developed diarrea that lasted a week. No ordinary diarrea either - this kind produced INSTANT diaper rash - burning red.

The next infection they tried amoxicillin, and her body responded much quicker with painful diarrea after about 4 days. (I later learned that while the first allergic reaction may be relatively benign, further exposure can create more violent reactions much faster). The dr. took her off that drug and since her ear infection looked better, left her off medication.

Soon after we were in for a sinus infection. Livia still had tummy troubles from the other medication. We tried Cefzil. BIG mistake. Livia was so ill. She wasn't dehydrated or anything, but her bottom was so red and painful and she had diarrea about every 10 minutes. The first two days on the drug were uneventful and then it hit hard. (I later learned that a 'true' penicillin allergy means that you will be allergic to cephalosporins, but that most people aren't truly allergic.) I didn't know that we shouldn't even be trying cephalosporins as a class (and neither did our dr) so we went through the gamut of Omnicef, Cefzil, and several other Cef___. Luckliy Zithromax exists!!! Otherwise I really don't know how we would have done this.

Somewhere in there I went to a doc in the box and a very sweet dr told me to get fresh acidophilus and give it religiously and also to stop diaper rash cream and buy Lotrimin instead. Priceless advice.

She had her tubes out at 12 months and her ear infections stopped with that, but sinus infections replaced ear infections, and I actually think those might be worse (they take so long to present and then a long time to get relief from medication). She finally got her adenoids out in May and has been a VERY healthy toddler since then!
Micaela
Mom to Livia (2.5 yrs, possible NS)

DO NOT RETREAT

Hi my name is Scott I was recently introduced to Noonan syndrome by my son Evan Newport. Evan has a lot of the stuff associated with the Syndrome. Evan is now 19 months and weighs 11.8kg.
Evan was in the hospital for 9.5 months. He is also an D.N.R.. Although there is a lot more history to Evan, I would like to share a few things my boy has taught me. The first thing He taught me was the warrior mentality. I made a plaque and placed it over his hospital crib and it looks like this :

- **Warriors know how to take on affliction**
- **Warriors may get knocked down but they always get back up**
- **Warriors know the greater the battle the greater the reward**

And about that D. N. R. stuff I had never heard that term before. So after the doctors explained that to me I thought and thought and prayed and prayed, what will I tell my little baby son . I went over to his bedside with the strength of a warrior and said to him I will tell you son what D.N.R. means to our family .

DO NOT RETREAT.

Well Evan is quite the teacher, I have learned many of life's lessons from him and am so happy I have a son like him .
I don't think I would have ever imagined a father could be so proud and blessed by a boy like him. Not only our family has been blessed but hundreds of nurses and many doctors and all of our friends and family have been touched too. Thank God for him .

Your new buddies the Newport's

DO NOT RETREAT

Dr. Noonan Requests Your Help

Dear Noonan Syndrome Adult,

I am conducting some research on Noonan syndrome, with a particular emphasis on growth. This questionnaire will be helpful and the response kept confidential. Your identity will not be used in any possible publication.
If you are willing to participate, please complete this questionnaire and return it to me.

Thanks,
Dr. J. Noonan
Dept. of Ped Cardiology
Room MN 470
University of Kentucky Medical Center
800 Rose ST
Lexington, KY 40536-0298

Patient Questionnaire for Adult with Noonan syndrome.

Hi, This is a little questionnaire from the department of pediatric Cardiology of University of Kentucky Children's Hospital. It's a questionnaire about Noonan syndrome, it contains some questions about your health and well being. It will only take about 10 minutes. (If you feel uncomfortable with any question or don't know the answer, fell free to leave it open.) We would be very grateful if you would want to fill out this questionnaire on behalf of a research we are doing on Noonan syndrome (You could ask a family member to help you if you want} .
Thank you!

1. What is your sex?

2. What is your birth?

3. What is your height? (Measured without your shoes)

4. What is your weight?

5. What was your birth weight?

6. What was your birth height?

7. What was the duration of your mother's pregnancy (gestation)?

8. How far did you go in school? (what grade, high school, college, university?)

9. Did you ever have learning difficulties or special education?

10. Are you employed? (If not please explain reason)
What kind of job do you have?

11. Have you had any heart problem in the past? If yes did this problem require surgery?

12. How is your health at the present time?

13. When was the last time you saw a physician?
(e.g.- primary health doctor, cardiologist, pediatrician)

14. Are you using any medication? (If yes please write down name and dose)

15. Have you ever used growth hormone? (If yes please tell us how long and at what age)

16. Are you married?

17. Do you have children? (If yes please write down sex and age of your children and if they have Noonan syndrome)

18. Does one of you family members have Noonan syndrome? Who?

19. For females: at what age did you start having your periods?
For males: At what age did your voice lower?

At what age did you start shaving?

20. Did you ever have any psychological problems?
(If yes please describe.)

At what age?

NEW RESEARCH STUDY AT THE HARVARD PARTNERS CENTER FOR GENETICS AND GENOMICS (HPCGG)!

Have you or your child been diagnosed with **NOONAN SYNDROME PULMONARY VALVE DISEASE** OR **HYPERTROPHIC CARDIOMYOPATHY?**

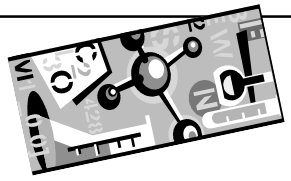
The goal of this study is to understand the gene changes that can lead to Noonan syndrome and related disorders. Changes in one gene have been identified in many people with Noonan syndrome. We would like to know if others with Noonan syndrome and related disorders also have mutations in this gene. We would also like to know more about you, your medical issues, and your family history to determine if certain features are associated with particular gene mutations.

Involvement in the study would require a referral to one of the research centers at Brigham and Women's Hospital, Massachusetts General Hospital, or Children's Hospital Boston or a visit to your own geneticist. Your physical exam, medical history, and family history would be reviewed. One sample of blood (3 teaspoons for adults, 2 teaspoon for children, 1 teaspoon for infants) would be required. If you have never had a cardiac or renal ultrasound these studies would be arranged.

The results of all of the testing will be made available to you by a geneticist or genetic counselor associated with the study.

With your permission, we will establish cell cultures and DNA to be stored at HPCGG in the Laboratory of Molecular Medicine.

Please have your physician contact **Amy Roberts, MD 617-525-5768** (aeroberts@partners.org) for more information.



RESEARCH OPPORTUNITIES CONTINUES

We need research volunteers! We are looking for adults and teenagers with Noonan syndrome who would be willing to undergo a skin biopsy (removal of a small piece of skin from the arm). We can also enroll children who are undergoing heart surgery. The purpose of the study is to understand the effects of the gene changes in Noonan syndrome on the way in which cells work. For more information, please contact Dr. Bruce Gelb at the Mount Sinai School of Medicine.

Tel: 212-659-6705. E-mail: bruce.gelb@mssm.edu

IN THE NEWS NOONAN SYNDROME AND A RARE FORM OF LEUKEMIA

The research program in the Gelb laboratory concerning Noonan syndrome continues to be very active. This program recently was approved for support from the National Institutes of Health for a five-year award as well as a two-year award from the March of Dimes. The most important recent discoveries relate to blood cell production problems that are associated with Noonan syndrome. Study of five children with Noonan syndrome and a rare form of leukemia as well as two other kids with short stature, pulmonary stenosis and that same blood disease revealed that all had inherited abnormalities in the Noonan syndrome gene (called *PTPN11*). It also appeared that there was a particular mutation that predisposed to the leukemia since five of seven had that DNA change while less than 2% of all children with Noonan syndrome had it. This finding has also led to new research concerning leukemia. It now appears that mutations in the *PTPN11* gene acquired in the bone marrow after birth are an important cause of some blood disorders in childhood. This work is described in a forthcoming publication in *Nature Genetics*.

Current efforts in the Gelb lab are directed towards understanding how *PTPN11* mutations result in the specific problems observed in patients with Noonan syndrome, hopefully leading to new and better ways of treating certain aspects of the disorder. Efforts are also in progress to discover the genetic cause for the 50% of Noonan syndrome not attributable to *PTPN11* abnormalities.

For more information, please contact Dr. Bruce Gelb at the Mount Sinai School of Medicine.

Tel: 212-659-6705. E-mail: bruce.gelb@mssm.edu

Will my child with Noonan syndrome be cognitively impaired (mentally

A common question parents have when told that their child has Noonan syndrome

- **Will my child with Noonan syndrome be cognitively impaired (mentally retarded)?**

In information published about Noonan syndrome it was typically said that people with Noonan syndrome were mentally retarded.

One of the first documents published by our group in 1996 recognized and stated that our children "most often have normal intelligence, and approximately 1/3 of individuals with Noonan syndrome will have learning disabilities and some will have mental retardation." [1]

In 1999 it was revealed the more severe cardiac defect and more evident facial and skeletal anomalies, was associated with a specific pattern of deficits and capacities in cognitive functioning.[2]

A paper published in 2002 uses these words "varying degrees of mental retardation" as a characterization of people with Noonan syndrome.[3]

As a group, we are in a unique position of having an opportunity to validate and improve the educational outcomes and treatment of people with Noonan syndrome. **However, we need your help.**

Here is what **you can do**, mail TNSSG a copy of all non-medical results from evaluations of affected individuals in your family. These would include but are not limited to tests in these areas:

- Intellectual/Cognitive Functioning
- Academic Performance
- Communication
- Motor Skills
- Sensory Status
- Health/Physical Status
- Functional Skills
- Emotional/Social/Behavior Development

All individual results are confidential. Dr. Thomas Baumgartner* has agreed to review our collected records with the express purpose of presenting the initial results at our 2004 conference. So, act today, collect and copy your reports and put them in the mail! (see address below)

1 Maura Kenton, MS Eric Wulfsberg, MD, TNSSG, Inc. Understanding Noonan syndrome A Parents Guide 1996

2 Van der burgt I, Toonen G, Rossenboom N, Assman-Hulsmans C, Gabreels F,Otten B, Brunner HG, Patterns of Cognitive functioning in school-aged children with Noonan syndrome associated with variability in phenotypic expression. J Pediatr 1999; 135: 707-713

3 M. Menahe, R. Arbel, D. Raveh, R. Achiron and S. Yagel , Poor prenatal detection rate of cardiac anomalies in Noonan syndrome Ultrasound Obstet Gynecol 2002; 19: 51-55

*Dr. Baumgardner is a clinical neuropsychologist in private practice in Lutherville, Maryland where he specializes in the assessment and treatment of children and adolescents with behavioral, learning, emotional, and cognitive disabilities. He received his Doctorate from the California School of Professional Psychology, including Internship and Post-doctoral training at the Kennedy Krieger Institute. From there he joined the research team of the Learning Disabilities Research Center at KKI, where he studied children and families with Turner's Syndrome, Fragile X Syndrome, Tourettes Syndrome, Neurofibromatosis Type-I, and Reading Disability. While remaining involved in clinical research and publication, Dr. Baumgardner's clinical work includes providing neuropsychological evaluations for primarily children but also adults. He is part of a multidisciplinary group of psychologists, psychiatrists, social workers, and behavioral pediatricians located at Johns Hopkins at Greenspring Station.

When mailing reports please make sure that your name and contact information is included, in case we have any questions.
Reports should be mailed to
TNSSG, Inc. (Reports)
P O Box 145
Upperco, MD 21155 USA

Knowledge and understanding leads to positive results for people of all abilities. Find out how you can help insure positive results. Be a part of the answer.

DESCRIPTION (FILL IN AND SEND WITH ORDER FORM)	#	$$ DUE
Growth Hormone in Noonan syndrome by Kees Noordam The studies presented in this thesis were funded by Pharmacia B.V., Woerden. Publication of this thesis was financially supported by Pharmacia B. V. , Woerden and FBW Kindergeneeskunde Nijmegen. - **$25.00 (Book)**		
Noonan Syndrome A Parents Guide- Excellent booklet written in easy to understand language, produced by The Noonan Syndrome Support Group, Inc.(1 Free with each parent package) - Additional books **$4.00 (Book)**		
Cómo Comprender El Síndrome De Noonan Guía Para Los Padres- Preparada Para El Grupo De Ayuda Del Síndrome De Noonan (Noonan Sydrome Support Group, Inc.) (1 Free with each parent package) - Additional books **$4.00 (Book)**		
The Many Faces of Noonan Syndrome Excellent booklet with photographs of people of various ages affected by Noonan syndrome. Produced by The Noonan Syndrome Support Group, Inc. -**$4.00 (Book)**		
Another Noonan Connection- A cookbook of favorite recipes (over 250 pages) from the families and friends of TNSSG, Inc. Produced by The Noonan Syndrome Support Group, Inc. **$10.00 (only**		
The Noonan Support Group Pin - This pin is shaped like a heart and within the heart is a box with the group's logo. The pin is set on a gold background. **$2.00**		
Noonan-syndrome Characteristics Development, and Intervention - by Dr. Stephen von Tetzchner, Center For Rare Disorders, The National Hospital, Norway: This book is a comprehensive guide that covers the many aspects of Noonan syndrome. **$20.00** "IF YOU ARE AFFECTED BY NOONAN SYNDROME YOU SHOULD OWN THIS BOOK" "THE MOST COMPREHENSIVE SOURCE , OF INFORMATION ABOUT NS		

(Compact Disks) Recording of individual speakers who presented at the 2002 Conference. Each disk is approximately 60 minutes long. $5.00 each	# @ $5.00	$$ DUE
CD: Dr. Steve Band: Director, Division of Pediatric Psychology and Neuropsychology, Mount Washington Pediatric Hospital One of the most common questions he has been asked by parents is how they can promote healthy self-esteem in their children with special needs. It is an important question that remains relevant today.		
CD: Dr. Thomas Baumgardner: Clinical neuropsychologist. He specializes in the assessment and treatment of children and adolescents with behavioral, learning, emotional, and cognitive disabilities. He is part of a multidisciplinary group of psychologists, psychiatrists, social workers, and behavioral pediatricians located at Johns Hopkins at Greenspring Station.		
CD: Dr. Bruce Gelb: The Arthur J. and Nelly Z. Cohen Professor of Pediatrics Professor of Human Genetics. Director Cardiovascular Genetics Program, Mt. Sinai School of Medicine, New York, NY.		
CD: Dr. Bryan Hall: Professor Emeritus Department of Pediatrics Division of Genetics and Dysmorphology, University of Kentucky, Lexington, KY. Special diagnostic interests: multiple congenital anomaly syndrome identification and teaching thereof.		
CD: Dr. Dolores Njoku: Pediatric Anesthesiologists on Staff at Johns Hopkins, Baltimore, MD. Research interests include the Immune effects of anesthetics		
CD: Dr. Jacqueline Noonan: University of Kentucky Medical Center, Lexington, KY. Professor of Pediatrics in the Division of Pediatric Cardiology.		
CD: **Dr. Alicia Romano:** Director of Pediatrics Endocrinology Our Lady of Mercy Medical Center Bronx, NY.		
CD: Dr. Frank E. Schafer :Associate Professor of Pediatrics, MCP Hahnemann University School of Medicine; Director General Hematology Clinic and Bleeding Disorders Program, St. Christopher's Hospital for Children Philadelphia, PA.		
CD: Dr Judith Allanson: Clinical geneticist with a longstanding interest in Noonan Syndrome. Her research focuses on the face: how it changes with age; how we evaluate facial appearance; how important knowledge of facial change is in the diagnosis of Noonan Syndrome.		

TNSSG ORDER FORM: PLEASE PRINT

NAME:_____

MAILING ADDRESS: _____

CITY: _____, STATE: _____ ZIP: _____

AREA CODE : _____TELEPHONE NUMBER :_____

E-MAIL ADDRESS: _____

____ Check MAKE PAYABLE TO: TNSSG, Inc. **OR** For your convenience Discover ___ Visa ___ Master Card _____

_____ **4 DIGIT EXPIRATION DATE** ____ / ____

PRINT NAME AS IT APPEARS ON CREDIT CARD **MONTH / YEAR**

__ __ __ __ - __ __ __ __ - __ __ __ __ - __ __ __ __

ACCOUNT NUMBER

_____

AUTHORIZED CARDHOLDER SIGNATURE

IN US DOLLARS PLEASE INDICATE : TOTAL FOR ITEMS PURCHASED $ _____

TOTAL SHIPPING COST # ITEMS X $ 3.00 $ _____ + TAX DEDUCTIBLE CONTRIBUTION $ _____

TOTAL AMOUNT $_____

RETURN COMPLETED INFORMATION TO: TNSSG, P O BOX 145, UPPERCO, MD 21155
QUESTIONS? Telephone: 888-686-2224 OR 410-374-5245 OR **Email:** wandar@bellatlantic.net

PLEASE PRINT CONTACT FORM

____ I want to continue to receive information from The Noonan Syndrome Support Group, Inc.
____ I want TNSSG, Inc. to send an information package to the following person.
____ I want to continue to be included on the People You Can Call List*.
____ I want to be added to the People You Can Call List*.

♥LAST NAME: _____
FIRST NAME: _____
♥MAILING ADDRESS:_____
_____CITY: _____
STATE:_____ZIP:_____ COUNTRY:
_____
♥PHONE NUMBER:_____ - _____
E-MAIL:_____
♥ UPDATE/CHANGE: _____

HOW ARE YOU AFFECTED? (please indicate)

♥Directly Affected __(an adult with NS)
♥Indirectly Affected __ (a parent or guardian of a child with NS.)
♥G.R.A.N.S ___(Grandparents Relatives Advocating for NS.)
♥N.A.P. ___(Noonan Angel Parents/ People).
♥Professionals ___ (doctors, teachers etc.)

***CHOOSE ONE** *

♥ ADD MY NAME TO THE CONTACT LIST AND WEB SITE CONTACT PAGE : _____
♥ ADD MY NAME TO THE CONTACT LIST ONLY
♥ NAME OF PERSON AFFECTED WITH NS
_____
♥ DATE OF BIRTH: ___/___/___
♥ ___ Inherited: _____Sporadic Occurrence/ Mutation

♥ NAME OF PERSON AFFECTED WITH NS
_____
♥ DATE OF BIRTH: ___/___/___
♥___ Inherited: _____Sporadic Occurrence/ Mutation
♥ NAME OF PERSON AFFECTED WITH NS
_____
♥ DATE OF BIRTH: ___/___/___
♥___ Inherited: _____Sporadic Occurrence/ Mutation

I HEREBY AUTHORIZE RELEASE OF MY NAME, MY CHILD'S NAME AND THE INFORMATION ON THIS FORM TO THE NOONAN SYNDROME SUPPORT GROUP AND THE FAMILIES INVOLVED THEREIN.

♥SIGNATURE:
_____
_DATE: _____

RETURN COMPLETED INFORMATION TO: TNSSG, P O BOX 145, UPPERCO, MD 21155
QUESTIONS? Telephone: 888-686-2224 OR 410-374-5245 OR **Email:** wandar@bellatlantic.net

Our Web site has been visited by over 100,000 people! We have given people another source for information! If not for the Web site, and all the attached material, people would still be looking for information about Noonan syndrome. A special thank you to Eugene K. As our former Web manager, he has created a place I am glad to call ours.

We're on the web! http://www.noonansyndrome.org Our Gallery of Stars has changed, visit us today.

WANT TO 'TALK' TO MORE THAN 200 PEOPLE AFFECTED BY NOONAN SYNDROME?

- ♥ ADULTS
- ♥ FAMILY MEMBERS
- ♥ YOU CAN JOIN FOR FREE!
- ♥ SIMPLY JOIN OUR GROWING 'LIST' OF PEOPLE WHO HAVE ALREADY SUBSCRIBED TO OUR INTERNET 'LIST'
- ♥ DETAILS ON HOW TO JOIN AND AVAILABLE OPTIONS FOLLOW...

We operate a list service (discussion forum). If you would like to subscribe, and be a part of our family, send an e-mail to

- ♥ **listserv@home.ease.lsoft.com**

with only the following command (words) in the message body:

- ♥ **subscribe noonan-syndrome**

That is it, nothing in the subject line, and only the words subscribe noonan-syndrome in the message body. (AOL subscribers also need to type a period "." in the subject line)

- ♥ To post a new message to the mailing list, address it to: NOONAN-SYNDROME@HOME.EASE.LSOFT.COM
- ♥ To receive a digested version, send an e-mail to: LISTSERV@HOME.EASE.LSOFT.COM in the message body write (without quotes) "SET NOONAN-SYNDROME DIGEST"
- ♥ To get a short acknowledgement that your message has been posted send a message to: LISTSERV@HOME.EASE.LSOFT.COM in the message body write (without quotes) "SET NOONAN-SYNDROME ACK NOREPRO"
- ♥ To turn off acknowledgements send a message to: LISTSERV@HOME.EASE.LSOFT.COM in the message body write (without quotes) "SET NOONAN-SYNDROME NOACK NOREPRO"
- ♥ To Un-subscribe or Sign off, send a message to: LISTSERV@HOME.EASE.LSOFT.COM in the message write (without quotes) "SIGNOFF NOONAN-SYNDROME"

Chit chat list

This list is intended for people affected by Noonan syndrome who want a place to communicate or chit/chat. Birthdays or poems, or anything that is important to your family.
Subscribe*:tnssgchitchat-subscribe@yahoogroups.com
Post message: nssgchitchat@yahoogroups.com
Unsubscribe:tnssgchitchat-unsubscribe@yahoogroups.com
List owner:tnssgchitchat-owner@yahoogroups.com

We also have a list for

- ♥ **Adults with Noonan syndrome.**
- ♥ **Kids with NS (moderated by an adult with NS)**
- ♥ **TNSSG information list**

For information on how to get on any of these lists, please contact wandar@bellatlantic.net

ADOPT A HIGHWAY FOR AWARENESS

Here is a suggestion from another non-profit organization-

The adopt a Highway program allows civic, family and business groups and non-profit community organizations to adopt a section of highway in their state for an agreed upon length of time. The group is responsible for a set number of litter pickups. Trash bags and disposable gloves are provided by the DOT, along with orange safety vests.

The Department of Transportation (DOT) will recognize the groups' efforts by erecting a sign with the groups name along the adopted section of highway. Adopt a Highway programs are available in most states, along with other similar programs that allow the planting of flowers or shrubs. Contact the Department of Transportation or the State Highway Administration in your state for details.

Here is a way you can clean up your streets and promote awareness of The Noonan Syndrome Support Group, Inc.

WHO WILL BE THE FIRST FAMILY TO ADOPT HIGHWAY FOR THE NOONAN SYNDROME SUPPORT GROUP, Inc?

The Noonan Syndrome Support Group, Inc.

THE NOONAN CONNECTION Winter 2003

THE NOONAN SYNDROME SUPPORT GROUP.. Inc.
PO BOX 145
UPPERCO, MD 2115

WISH LIST

- **PICTURES AND STORIES FROM THE HEART FOR PUBLICATIONS AND THE WEBSITE**
- **AUCTION ITEMS FOR THE 2004 CONFERENCE**
- **AIRFARE OR TRAVEL AWARDS FOR TRAVEL TO THE CONFERENCE IN 2004**
- **POSTAGE AND PRINTING FEES FOR MAILING TO FAMILIES**
- **GRANT WRITER**
- **PHLEBOTOMIST FOR THE 2004 CONFERENCE**
- **GIFTS ITEMS FOR THE SPEAKERS AND CHILDREN ATTENDING THE 2004 CONFERENCE**

Please remember to give to The Noonan Syndrome Support Group, Inc. We are working hard to increase research, find better treatments, and provide exceptional support to those affected by Noonan syndrome.

THANK YOU
MICHAEL T. BLAIR, CPA, CFP AND STAFF
OF
BLAIR & ASSOCIATES, INC
1101 BUSINESS PARKWAY SOUTH
WESTMINSTER, MD 21157
PHONE 410-876-0076 FAX:410-876-0078
E-MAIL: MBLAIR@BLAIR-CPA.COM

THANK YOU
RACHEL A. ISRAEL, ESQ. , LLM
OF
MURPHY, HESSE, TOOMEY & LEHANE, LLP
ATTORNEYS AT LAW
CROWN COLONY PLAZA 300 CROWN COLONY DRIVE QUINCY, MA 02169
WORLD TRADE CENTER EAST, BOSTON MONARCH PLACE, SPRINGFIELD
TEL: 617-479-5000 FAX: 617-479-6469

HERE ARE SOME OF THE WAYS YOU CAN SUPPORT TNSSG, INC.

- **MAKE A TAX DEDUCTIBLE CONTRIBUTION**
- **DESIGNATE TNSSG, INC. ON YOUR PLEDGE FORM WHEN GIVING TO THE UNITED WAY OR COMBINED FEDERAL CAMPAIGN**
- **ARRANGE FOR A MATCHING FUNDS DONATION THROUGH YOUR EMPLOYER**
- **HONOR A LOVED ONE OR CLOSE FRIEND WITH A BEQUEST IN THEIR NAME**
- **ORGANIZE AND PLAN A FUND RAISER**
- **PARTICIPATE IN A FUND RAISER**
- **MAIL INFORMATION TO OTHERS ABOUT NOONAN SYNDROME**
- **TALK TO OTHERS ABOUT NOONAN SYNDROME**
- **BECOME A CONTACT, FILL OUT THE CONTACT RELEASE INFORMATION FORM.**

DO SOMETHING -WE NEED YOUR CONTINUED SUPPORT- BE A PART OF THE SOLUTION
"The only disability is a bad attitude."