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The newsletter of  
Swan USA

**"Our Swan is disjoined, like many families of children who have a  
Syndrome Without A Name  
Help us to make that Connection"**

Winter 2004

Issue #1

## Welcome To Swan USA

Some of you may already know a bit about Swan. Swan was intended to be a small local group in the United Kingdom. It grew rapidly, after 12 months it already had 450 members and is now a national support group with over 900 members.

It was started about 7 years ago by Elizabeth Swingwood. Lis is the grandmother of little girl who has a syndrome without a name. After watching what her daughter and granddaughter had experienced for 9 years, she wanted children without a diagnosis to have the same recognition as those with Downs Syndrome and other well-known syndromes.

It is estimated that 30 to 40 percent of special needs children do not have a specific diagnosis. Some may receive a diagnosis, but many will live in a gray world of never knowing. This won't stop many from searching and hoping that one day they will reach the end of undiagnosed road.

This road is often traveled alone, this was one of many things that sparked me to respond to a letter I received from Lis. Lis expressed the need for help to get Swan in other countries. I thought wow this could heighten our chances of finding another like my daughter. It could bring people from all over the world together who are dealing with similar issues as me. I had also previously started a small e-mail group and site for those dealing with a not known diagnosis. This came about after years of searching and feeling we were one of many that couldn't find a place to belong.

I found many scattered around in different groups just like me. I was in different groups for many of the characteristics my daughter has. My daughter is now 8, and still with out a specific diagnosis. Lorna is described by the geneticist as having multiple congenital anomalies, they say she is unique and they are stumped.

Lorna was mine and my husbands first born, we have come a long way since then. We now have a 4 year old son and a new baby girl born in august. I stay at home with my children, and though it seems I might have free time on my hands that isn't the case. I'm not experienced in writing newsletters, but I hope to do 3 newsletters a year starting off.

Wishing you all a happy healthy New Year,  
Amy Clugston

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I welcome you all to add your stories, pictures, worries and such.



My daughter Lorna is now 8 years old. Her major features are microcephaly, heart defect from birth to 4, delayed bone age of more than 3 years, a combination of speech disorders with good receptive skills, delayed motor abilities, and cognitive impairment.

She loves swimming, horses, blues clues, barbie. She enjoys doing homework like coloring, writing, and reading. Of course her reading consists of pretending, as she isn't able to read, but wants to so bad.

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## What does Swan International have to offer?

An International database is being worked on; when completed we will have a better chance at finding others with similar issues. When SWAN is well recognized by doctors and parents we will be better understood when we say our children have an undiagnosed syndrome or condition. More recognition may also spark more doctors to be interested in helping find answers and possibly find treatments for some conditions. Many will now have a sense of belonging instead of feeling alone. We will have the opportunity for us all to come together, instead of being scattered in different groups. There are many more possible benefits to come in the future, like conferences, gatherings and such.

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## Swan USA State

I will continually be looking for Swan State Helpers. Below is a list of stuff we will need these helpers for. This could be one person or many to divide tasks up. One doesn't need to do all of these, each of the areas will differ.

1. Help getting the word out, by sending information to genetic counselors and families.
2. Be a contact person for families in your State or Region.
3. Possibly send inserts in the newsletters with state or regional resources and such.
4. When we have enough swan families, we may need support group organizers for different areas
5. Be a in support system with other state helpers.

Together we will build our community.

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## SWAN State Contacts

Michigan - Amy Clugston  
amy76jo@yahoo.com

California - Annette Humphreys  
annette@customracestuff.com

New York - Sheila Hayes  
hayes@juno.com

Wisconsin - Bridgette & Bryon Shriek  
sillychick1@hotmail.com

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## MUMS

Mothers United for Moral Support

MUMS is a national Parent to Parent Network. They will match your information with others in their database of 18,000 families. This service cost only \$5, you will receive the names, addresses, phone numbers and the symptoms that matched yours. They also have a newsletter, which costs \$15 a year for parents. The newsletter is called matchmaker and mostly consists of families writing about their children, in hopes to find someone to connect too. They often have a picture of their child to go with their messages.

Mother United for Moral Support Inc.  
c/o Julie Gordon  
150 Custer Court  
Green Bay, Wisconsin 54301-1243

<http://www.netnet.net/mums>  
[mums@netnet.net](mailto:mums@netnet.net)  
Toll free for parents  
1- 877- 336 -5333

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## National Library for the blind, physically handicapped and learning disabled

<http://www.loc.gov/nls/>  
1-800-424-8567

The National Library is for those who are blind or have a physical handicap that effects them holding a book. The learning disabled are also eligible; they will need the application sign by a medical doctor. Their service offers books in Braille and on tape for the young and old. There isn't one central location, but rather many different places in different states. So if you call the above phone number or go to the web address you will be given your state or regional information to contact. Then you will need to fill out an application and send it back to the state agency.

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## Personal Ponies

**Nov. 1 - April 30**

Marianne Alexander, National Director  
220 PRESIDENT'S CUP WAY #101  
St. Augustine Beach, FL 32092  
904-940-7347

**May 1 - October 31**

Marianne Alexander, National Director  
1638 Housatonic Street  
Pittsfield, MA 01201  
413-499-1934  
[personalponies@earthlink.net](mailto:personalponies@earthlink.net)  
[www.personalponies.org](http://www.personalponies.org)

This organization gives children Uk shetland ponies. The ponies are not offered to just a small group of children but to all that are differently-abled. This could be a child with emotional issue, birth defects or one suffering injuries from an accident the list goes on. Children can't ride the ponies if they are over 30lbs, but they make exceptional companions. Some would call it animal therapy. There is a long waiting list and children with critical or terminal conditions will get first priority.

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## The Experience of Living Without a Diagnosis for Parents of Children with Disabilities

A PhD Study

Nicola Coates

Community Health Sciences

University of Edinburgh

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Nicola has invited us to take part in her research study. She is from the UK but has extended her invite to others outside of the UK. There is an information packet available, which will explain the study in more detail. If you would like a copy sent to you, contact me by phone, mail or e-mail. You may also contact Nicola by the e-mail above.