

WORDS

The Newsletter of the Worster-Drought Syndrome Support Group

ISSUE 13

A Message from the Chairman

Sunday the 22nd of June was the day of our Teddy Bears Picnic held at Sunfield School, south west of Birmingham. It was nice to see all the families that had made the journey but the award for the furthest distance travelled goes to Louise Smith who came from the Shetland Islands. Well done, it was good to meet you. We have had many nice comments about the picnic day and, all in all, it seems that everyone I have spoken to gained something from the time spent at Sunfield. I would like to once again thank the staff and residents of the school for allowing us to take over their fantastic facilities. If you would like to make any comments, good or bad, please take a minute and fill in the feedback form (inside the AGM pack) and post it to the address on the form. This will enable us to fine-tune the next family day.

On that subject, we have provisionally booked London Zoo for June next year for a full family day complete with a panel of speakers. The details are being put together as we speak and we are hoping to, once again, have full funding for the day. It may, however, be necessary to charge a small fee to cover administration costs. We will let you know nearer the time. Fund-raising is extremely important so we can provide the help and support that is asked of us and to help fund further research that will benefit us all. To this end, as discussed at the AGM, we have formed a sub committee to look at all aspects of fund-raising. The chairman of the committee is Graham Spencer who can be contacted by e-mail on Fundraising@wdssg.org.uk. If you have any ideas or thoughts

on fund-raising, or are able to spend some time helping Graham and his team, please get in touch with him or any committee member.

Well life continues with the usual discussions with our Local Education Authority regarding the future schooling of Christopher, our son who has WDS. It's unfortunate that we have to go through this every term even though we know they will all come round to our way of thinking eventually. It's a bit like the bureaucrats have to be awkward just to keep in practice. I will keep you posted.

There won't be another newsletter now until after the summer so please have a good break and don't forget the sun cream (unless it's raining of course).

Gavin Leech



One of the guests at the Teddy Bears Picnic

Thanks

The committee would like to thank everyone who has contributed to this newsletter, special thanks go to Don Meyer, Director of the Sibling Support Group who has kindly given us permission to reproduce his article for our members.

If you have an article or poem that you would like to be published in the next issue of WORDS then please contact Graham Spencer at graham@bt.com or write to 12 Priory Avenue, Pettswood, Kent BR5 1JF

Closing Date for next issue is November 1st 2003

News

Fundraising

We have set up a sub-committee to help us deal with Fundraising. We **desperately** need volunteers to come on board with us. The money raised will go towards a much needed research project into Worster-Drought Syndrome, which is to run by Great Ormond Street. Please contact Graham Spencer on Fundraising@wdssg.org.uk or Hayley Herman on Haymarcons@aol.com if you have any ideas or would like to get involved in any way.

Feedback Forms

At the last AGM/Picnic Day we gave you an information pack, which included a Feedback Form. We haven't yet received the forms back from many of you. Please can you fill this in and return as soon as possible.

Our First Workshop

The first workshop has been booked on the 13th October 2003 at ACE Centre Advisory Trust, 92 Windmill Road. Headington, Oxford, OX3 7DR from 11.30am 1.00pm. The workshop will be run by Andrew Lesley Deputy Director/Teacher and Rachael Moore, Speech and Language Therapist. There are only 6 places available and we have 4 people interested at the moment. If you want to come DON'T DELAY phone Monique Lauder on 0208 428 6706 or email her on monique.lauder@bopenworld.com. Obviously if this workshop is successful we will do others but we need your time and support to make it work.

AGM/Fun Day 2004

We have provisionally booked London Zoo on June 12th 2004 for our AGM/Fun Day for the whole family. As discussed in the AGM just gone, venues were extremely hard to find and London Zoo seemed the most suitable. If you do have any suggestions please contact Monique Lauder on 0208 428 6706 who is responsible for this event. We will have more information for you nearer the time but please book it in your diary for next year.

Teddy Bears Picnic

Well the AGM/Teddy Bear's Picnic Day was another WDS success. The sun shone, which was a amazing as the early mid morning saw torrential rain! The venue, Sunfield School, Clent, Birmingham, proved to be excellent for our needs. The two rooms, which housed the AGM and the entertainment/Tea and Coffee room, were great and everyone looked relaxed and comfortable with the surroundings.

The AGM went without any glitches. It was speedily got through, which, as you may all agree, is a good thing. The topic of conversation was fundraising, which we urgently need volunteers for. Also discussed was the AGM 2004 and any suggestions for venues. Whilst this was going on the children were entertained by PJ the Clown who kept the children in tow and some of the adults! The arts and crafts on offer were wonderful and the children seemed to be enjoying themselves.

After the AGM we went outside and joined our Teddy's for the picnic on, what we all agreed, was a glorious hot summers day (were we really in the UK!). PJ the Clown was still on duty and there was also face painting for the brave and the some of the staff at Sunfield accompanied children to the outdoor play area.

We were thrilled with the attendance figures. All the children and adults who came really looked like they were having a wonderful time and the committee felt like we accomplished our goal of making the Teddy Bear's Picnic/AGM a day to remember.



What siblings would like parents and service providers to know

In the United States, there are over six million people who have special health, developmental, and mental health concerns. Most of these people have typically-developing brothers and sisters. Brothers and sisters are too important to ignore, if for only these reasons:

These brothers and sisters will be in the lives of family members with special needs longer than **anyone**. Brothers and sisters will be there after parents are gone and special education services are a distant memory. If they are provided with support and information, they can help their sibs live dignified lives from childhood to their senior years.

Throughout their lives, brothers and sisters share many of the concerns that parents of children with special needs experience, including isolation, a need for information, guilt, concerns about the future, and caregiving demands. Brothers and sisters also face issues that are uniquely theirs including resentment, peer issues, embarrassment, and pressure to achieve.

Despite the important and life-long roles they will play in the lives of their siblings who have special needs, even the most family-friendly agencies often overlook brothers and sisters. Brothers and sisters, often left in the literal and figurative waiting rooms of service delivery systems, deserve better. True "family-centered" care and services will arrive when siblings are actively included in agencies' functional definition of "family."

The Sibling Support Project facilitated a discussion on SibNet, its listserv for adult siblings of people with disabilities, regarding the considerations that siblings want from parents, other family members, and service providers. Below is a discussion of themes discussed by SibNet members and recommendations from the Sibling Support Project:

1. *The Right to One's Own Life.* Throughout their lives, brothers and sisters may play many different roles in the lives of their siblings who have special needs. Regardless of the contributions they may make, the basic right of siblings to their *own* lives must always be remembered. Parents and service providers should not make assumptions about responsibilities typically-developing siblings may assume without a frank and open discussion. "Nothing about us without us" a phrase popular with self-advocates who have disabilities applies to siblings as well. Self-determination, after all, is for everyone including brothers and sisters.

2. *Acknowledging Siblings' Concerns.* Like parents, brothers and sisters will experience a wide array of often ambivalent emotions regarding the impact of their siblings' special needs. These feelings should be both expected and acknowledged by parents and other family members and service providers. Because most siblings will have the longest-lasting relationship with the family member who has a disability, these concerns will change over time. Parents and providers would be wise to learn more about siblings' life-long and ever-changing concerns.

3. *Expectations for Typically-Developing Siblings.* Families need to set high expectations for all their children. However, some typically-developing brothers and sisters react to their siblings' disability by setting unrealistically high expectations for themselves and some feel they must somehow compensate for their siblings' special needs. Parents can help their typically-developing children by conveying clear expectations and unconditional support.

4. *Expect Typical Behavior From Typically-Developing Siblings.* Although difficult for parents to watch, teasing, name-

calling, arguing and other forms of conflict are common among most brothers and sisters - even when one has special needs. While parents may be appalled at siblings' harshness toward one another, much of this conflict can be a beneficial part of normal social development. A child with Down syndrome who grows up with siblings with whom he sometimes fights will likely be better prepared to face life in the community as an adult than a child with Down syndrome who grows up as an only child. Regardless of how adaptive or developmentally appropriate it might be, typical sibling conflict is more likely to result in feelings of guilt when one sibling has special health or developmental needs. When conflict arises, the message sent to many brothers and sisters is, "Leave your sibling alone. You are bigger, you are stronger, you should know better. It is your job to compromise." Typically-developing siblings deserve a life where they, like other children, sometimes misbehave, get angry, and fight with their siblings.

5. *Expectations for the Family Member with Special Needs.*

When families have high expectations for their children who have special needs, everyone will benefit. As adults, typically-developing brothers and sisters will likely play important roles in the lives of their siblings who have disabilities. Parents can help siblings now by helping their children who have special needs acquire skills that will allow them to be as independent as possible as adults. To the extent possible, parents should have the same expectations for the child with special needs regarding chores and personal responsibility as they do for their typically-developing children. Not only will similar expectations foster independence, it will also minimize the resentment expressed by siblings when there are two sets of rules - one for them, and another for their sibs who have special needs.

What siblings would like parents and service providers to know

6. **The Right to a Safe**

Environment. Some siblings live with brothers and sisters who have challenging behaviors. Other siblings assume responsibilities for themselves and their siblings that go beyond their age level and place all parties in vulnerable situations. Siblings deserve to have their own personal safety given as much importance as the family member who has special needs.

7. **Opportunities to Meet**

Peers. For most parents, the thought of "going it alone," raising a child with special needs without the benefit of knowing another parent in a similar situation would be unthinkable. Yet, this routinely happens to brothers and sisters. Sibshops, listservs such as SibNet and SibKids, and similar efforts offer siblings the common-sense support and validation that parents get from Parent-to-Parent programs and similar programs. Brothers and sisters like parents like to know that they are not alone with their unique joys and concerns.

8. **Opportunities to Obtain**

Information. Throughout their lives, brothers and sisters have an ever-changing need for information about their sibling's disability, and its treatment and implications. Parents and service providers have an obligation to proactively provide siblings with helpful information. Any agency that represents a specific disability or illness and prepares materials for parents and other adults should prepare materials for siblings and young readers as well.

9. **Sibs' Concerns about the**

Future. Early in life, many brothers and sisters worry about what obligations they will have toward their sibling in the days to come. Ways parents can reassure their typically-developing children are to make plans for the future of their children with special needs, involve and listen to their typically-developing children as they make these plans, consider backup plans, and know that siblings' attitude toward the extent of their

involvement as adults may change over time. When brothers and sisters are "brought into the loop" and given the message early that they have their parents' blessing to pursue their dreams, their future involvement with their sibling will be a choice instead of an obligation. For their own good and for the good of their siblings who have disabilities, brothers and sisters should be afforded the right to their own lives. This includes having a say in whether and how they will be involved in the lives of their siblings who have disabilities as adults, and the level, type, and duration of involvement.

10. **Including Both Sons and Daughters.**

Just as daughters are usually the family members who care for aging parents, adult sisters are usually the family members who look after the family member with special needs when parents no longer can. Serious exploration of sharing responsibilities among siblings including brothers should be considered.

11. Communication. While good communication between parents and children is always important, it is especially important in families where there is a child who has special needs. An evening course in active listening can help improve communication among all family members, and books, such as *How to Talk So Kids Will Listen and Listen So Kids Will Talk* and *Siblings Without Rivalry* (both by Adele Faber and Elaine Mazlich) provide helpful tips on communicating with children.

12. **One-on-One time with**

Parents. Children need to know from their parents' deeds and words that their parents care about them as individuals. When parents carve time out of a busy schedule to grab a bite at a local burger joint or window shop at the mall with their typically-developing children, it conveys a message that parents "are there" for them as well and provides an excellent opportunity to talk about a wide range of topics.

13. **Celebrate Every Child's Achievements and Milestones.**

Over the years, we've met siblings whose parents did not attend their high school graduation even when their children were valedictorians because the parents were unable to leave their child with special needs. We've also met siblings whose wedding plans were dictated by the needs of their sibling who had a disability. One child's special needs should not overshadow another's achievements and milestones. Families who seek respite resources, strive for flexibility, and seek creative solutions can help assure that the accomplishments of all family members are celebrated.

14. **Parents' Perspective is More Important than the Actual Disability.**

Parents would be wise to remember that the parents' interpretation of their child's disability will be a greater influence on the adaptation of their typically developing sibling than the actual disability itself. When parents seek support, information, and respite for themselves, they model resilience and healthy attitudes and behaviors for their typically-developing children.

15. **Include Siblings in the Definition of "Family."**

Many educational, health care, and social service agencies profess a desire to offer family-centered services but continue to overlook the family members who will have the longest-lasting relationship with the person who has the special needs the sisters and brothers. When brothers and sisters receive the considerations and services they deserve, agencies can claim to offer "family-centered" instead of "parent-centered" services.

16. **Actively Reach Out to Brothers and Sisters.**

Parents and agency personnel should consider inviting (but not requiring) brothers and sisters to attend informational, IEP, IFSP, and transition planning meetings, and clinic visits. Siblings frequently have legitimate questions

What siblings would like parents and service providers to know

that can be answered by service providers. Brothers and sisters also have informed opinions and perspectives and can make positive contributions to the child's team.

17. Learn More About Life as a Sibling. Anyone interested in families ought to be interested in siblings and their concerns.

Parents and providers can learn more about "life as a sib"

by facilitating a Sibshop, hosting a sibling panel, or reading books by and about brothers and sisters. Guidelines for conducting a sibling panel are available from the Sibling Support Project and in the Sibshop curriculum. Visit the Sibling Support Project's website for a bibliography of sibling-related books.

18. Create Local Programs Specifically for Brothers and Sisters.

If your community has a Parent-to-Parent Program or similar parent support effort, a fair question to ask is: why isn't there a similar effort for the brothers and sisters? Like their parents, brothers and sisters benefit from talking with others who "get it." Sibshops and other programs for preschool, school-age, teen, and adult siblings are growing in number. The Sibling Support Project, which maintains a database of over 200 Sibshops and other sibling programs, provides training and technical assistance on how to create local programs for siblings.

19. Include Brothers and Sisters on Advisory Boards and in Policies Regarding Families.

Reserving board seats for siblings will give the board a unique, important perspective and reflect the agency's concern for the well-being of brothers and sisters. Developing policies based on the important roles played by brothers and sisters will help assure that

their concerns and contributions are a part of the agency's commitment to families.

Fund Services for Brothers and Sisters. No classmate in an inclusive classroom will have a greater impact on the social development of a child with a disability than brothers and sisters will. They will be their siblings' life-long "typically developing role models." As noted earlier, brothers and sisters will likely be in the lives of their siblings longer than anyone longer than their parents and certainly longer than any service provider. For most brothers and sisters, their future and the future of their siblings with special needs are inexorably entwined. Despite this, there is little funding to support projects that will help brothers and sisters get the information, skills and support they will need throughout their lives.

Governmental agencies would be wise to invest in the family members who will take a personal interest in the well-being of people with disabilities and advocate for them when their parents no longer can. As one sister wrote: "We will become caregivers for our siblings when our parents no longer can. Anyone interested in the welfare of people with disabilities ought to be interested in us."

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Sibling Support Project

About the Sibling Support Project

The Sibling Support Project, believing that disabilities, illness, and mental health issues affect the lives of all family members, seeks to increase the peer support and information opportunities for brothers and sisters of people with special needs and to increase parents' and providers' understanding of sibling issues.

Our mission is accomplished by training local service providers on how to create Sibshops (lively community-based for school-age brothers and sisters); hosting workshops, listservs, and websites for young and adult siblings; and increasing parents' and providers' awareness of siblings' unique, life-long, and ever-changing concerns through workshops, websites, and written materials.

Based in Seattle since 1990, the Sibling Support Project is the only national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health and developmental needs.

For more information about Sibshops, sibling issues, and our workshops, listservs and publications, contact:

Sibling Support Project of the Arc of the US

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Jake and Ruby

I was asked to write a piece for WORDS about our experiences of having two children with WDS, where do I begin?

Jake was born in 1994, he weighed in at 10lb11oz's at birth. He was however a content happy baby and we had no cause for concern for many months. He did have a minor problem with drinking from a bottle, but that was solved by giving him a fast flow teet on his bottle. We were a bit concerned about his early development regarding sitting up, but were told not to worry that he was a bit of a lazy baby. He did sit unaided at 10 months, however by the time of his first birthday I was getting very concerned, his development was a lot slower than his peers. We referred him to the local Child Development Team & by the time he was 18months the community paediatrician agreed the he had slow development, but again we should not worry as he was a content & probably lazy little boy. In the mean time we had decided to try for another child, blissfully unaware of how affected Jake was.

When I was four months pregnant with Ruby, Jake had his first seizure, and within a couple of weeks had had several fits, & was in hospital suffering an extreme reaction to his medication. He spent four weeks in local & then GOS Hospital. He was so ill that we both agreed that we didn't care how fast or slow his development was we just wanted him home safe & well. Within a few months he did recover and by this time he was two & starting to walk, still he had no speech, although he made sounds & said Mama & Dada.

Ruby was born in Jane 1997, another heavy child but we both felt sure she was fine. She was very different to Jake as a baby, she was noisy, she moved more & had no problems drinking her milk. We had a wonderful summer, Ruby was a lovely baby & Jake

was had really recovered well after being so ill. Again it was not until the six month stage that we started to worry about her development. When at about seven months we started to think seriously there may be a problem my world was rocked. I kept on a brave face to the outside world but I just couldn't believe that my lovely little normal girl had problems. Thank God John was a rock, he was upset but probably more practical about things than me. At nine months Ruby had her first seizure, it was Easter weekend, Jake had just come home from hospital after having some fits, & granny had offered to keep Ruby for the night so we could concentrate on Jake. When we got the phone call to say Ruby was ill we were both very low. With both children poorly you have to keep going, we are so lucky to have our parents nearby, they were a huge help. That Easter will however always remain one of our worst memories, I guess Ruby was confirmed as having the same as yet undiagnosed condition.

A couple of weeks later we had an appointment with Prof. Neville, WDS was diagnosed for Jake & we were told it was a possibility that Ruby had the same condition however she was too young to diagnose. We left GOS with a name but no other information. To find there was a family support group & other people going through the same things was really reassuring, the family Day in 1998 gave us a lot of information, support & help.

Around this time 'Welcome to Holland' was printed in the newsletter. We both felt it was so appropriate to us, we had it stuck to the Fridge & read it a lot. Its in one of the early additions of WORDS and available on the web site.

When Jake was three he attended a main stream nursery, we kept him there for two terms, but it became very apparent that the

placement was unsuitable, Jake had a lovely time doing everything that he shouldn't, he was allowed to run from room to room and could not cope with the freedom & level of choice available. We had quite a struggle with the council to get him moved to a Special School. John was great at the meetings with the school & council, I'd find myself too choked to be able to speak and he just stayed determined & very single minded.

Jake started at this current school in Easter 1999, & the support he received and the moral support we received was fantastic. For the first time we were given advice & strategies to help with behaviour, but more importantly we were given a lot of hope. We did not hesitate about choosing this school for Ruby she started in the nursery when she was only two. Our experiences with Jake did make us so much more aware of Ruby's rights and we have valuable experience about the Statementing process.

I feel that we have been a lot more relaxed as parents with Ruby & willing to accept her limitations. With Jake I felt that we should be able to achieve more and you sometimes forget about fun & try too hard to be 'educational'. It takes a long time to come to terms with the fact that you can help your child but you can not cure them. When Jake was 3 we took him to BIBIC in Somerset, this organisation develop programs for children, the work is very intensive. We found that Jake had such a strong will we just ended up battling with him the whole time. I really felt if I could do this program with him, four or five times a day I would have amazing results. I was really disappointed when we admitted defeat, but Jake was rebelling against his program and we were all suffering.

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Jake and Ruby (cont.)

The practicalities of having two children with special needs is difficult. Its very difficult to go anywhere on my own with them, Ruby does not walk very well and Jake will run off given the opportunity. Even visiting a friend can be difficult as I need to keep an eye on Jake as he can be rough with other children, however Ruby needs watching as she can quietly get into a mess eating po-pori or potted plants!

We do at times feel isolated, we have a good family support but friends with similar age children are now regaining a lot of freedom, they can visit other friends with their children & have a relaxing time, if we were to go the dynamics of the visit would be very different.

My Mum and Dad have especially has helped us so much, with practical help as well as moral support. Mum expects us to go out weekly and is always there to baby sit (if we don't want to go out she wants an explanation!) this I'm sure has helped John & me through.

We feel a sense of isolation for our children, Jake loves to play with his normal friends but as the children get older they have their own friends & it is difficult to encourage them to come & play. Initially I found this really hurtful but Jake & Ruby are not bothered they are incredibly happy children they love company & I think are often happier with adult company.

Since starting to write this we have just had the Easter holidays. We went to Ireland for a week and had a lovely time. We were nervous about flying and nervous about staying with someone, but we had a wonderful time. I guess the children are growing up & although they are demanding, they are starting to mature. This holiday made us feel really optimistic about the future.

Donna

Beautiful Smile

Life is strange, he's silent and staring,
Struggling to feed, he needs cuddling and caring.

Tiny, tiny body, fragile to hold,
Wrap him up so he doesn't get cold.

Ice blue eyes looking at me,
I can't help wondering, what does he see?

He'll get bigger, a little bit each day,
We'll take any pain and throw it away.

Things are not right, he's getting behind,
People smile and try to be kind.

Eating, walking, speaking is hard,
Simple words from nursery, written on card.

Getting help means filling in form after form,
Daily medicine, twice a day is the norm.

Assistance is needed, all kinds of support,
Battles and wars all need to be fought.

Anger, shouting, screaming and crying,
Laughing, giggling, learning and trying.

He's at school now, we are trying to win,
Everyone loves his will to fit in.

We will succeed, it will take a while,
Oh, and by the way, he does have a beautiful smile.

Written anonymously by a member of the group. Copyright is reserved.