

# BREAKING BARRIERS

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## A Stutter

For as long as I can remember, I have stuttered. The act of speaking—a pleasurable activity for most people, a way of expressing thoughts and opinions—has always been a major challenge for me. This speech difficulty has caused me much pain and stress through the years. Allow me to share anecdotes to give you some idea of how stuttering has affected my life.

In second grade I had a teacher who was a strong advocate of “round robin oral reading.” She would choose a selection from our reading book and ask each student to read a paragraph aloud. We would begin in one corner of the room and keep going through the class until all the students had had a chance to practice reading out loud. This sounds innocuous enough, right? Isn’t it simply an example of a teacher giving her students opportunities to practice oral reading?

To this day, I can clearly recall the terror I felt as my turn to read came closer and closer. I remember counting ahead in the passage to see what letter was at the beginning of my paragraph. If it began with one of those few sounds I could easily pronounce, I would silently heave a sigh of relief. If, however, it began with a difficult sound, I would break out into a sweat as my turn came closer and closer. When I inevitably stumbled badly, I felt an overwhelming sense of failure. This happened over and over again that year and my self-concept dipped to an all-time low. It is still painful for me to think back to that time and dredge up those awful memories.

Through the years I developed ways to avoid speaking: arriving late to meetings, church services, and other public gatherings, and leaving immediately afterwards. When I had to speak, I developed ways of avoiding certain sounds that were difficult for me. For example, words beginning with the letter “N” have always been difficult for me to pronounce, and I have trouble saying the word “Nigeria.” Our family lived in Nigeria as missionaries for eight years and returned to Canada in 1993. In answer to the question “Where did your family live before you returned to Canada?” I’d often reply, “In Africa.” That was usually sufficient, but if the questioner was more persistent and asked, “Where in Africa?” I’d say, “West Africa.” That was almost always enough; but if the person asked, “Which country in West Africa?” I would have to say the dreaded word “Nigeria.”

In 1997 while looking through a local newspaper I noticed an advertisement for a local stuttering support group. I remember thinking, “There really are more people like me who have similar struggles.” I decided to go to a meeting and check it out. This decision was life changing. I met people who could relate to and understand my struggles and difficulties. They had some of the same avoidance behaviors I had. Through these people I learned about speech therapy, and in January 1998 I took a three-week speech therapy course.

One thing I learned in speech therapy was the value of being open about one’s stutter. I decided that it was important to talk openly with my



Jack Beekma

fourth-grade students about it. I realized that although I had been a classroom teacher for twenty-two years and had an obvious stutter, I had never spoken openly about it. As I look back on it now, the unspoken message I had been giving my students was “If you have a problem, try to hide it, don’t deal with it, and by all means don’t talk about it.”

I made three decisions. First, I decided to begin every school year by speaking openly with my students about my stutter. In each of the past four years that I’ve done this, the open sharing of my life creates an instant connection with the kids. Rather than seeing their teacher as

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## From the Director



In the last issue of BB I printed the church accessibility figures for the past seven years as reported by CRC church councils to the General Secretary on the accessibility questionnaire. Disability Concerns is responsible to synod for monitoring and reporting denominational progress in providing access for people with disabilities.

The questionnaires provide much more data than I could show in the last issue, so in this issue I show you all the data from just the current year's questionnaire. I cannot print all the figures from previous years because of space limitations, but we do have that data on file. Many of these results are given in the CRC Yearbook; complete results can be obtained from our office.

It is clear from 2003 figures that the questionnaire does not produce exact results and that there is room for personal judgment in completing it. For example, 57 churches offer signing for the deaf when requested, but only 46 churches claim to provide this service. The other 11 churches apparently do not have requests often enough that they count themselves as providing the service.

The answers to question 8 are not shown in the Year Book since that information is not helpful to visitors even though it is useful to our office in documenting denominational progress in breaking down barriers. The answers to all the other numbered questions are shown in the Year Book by means of the symbols printed under each church entry.

Yearbook Questionnaire Results (the database contains 996 churches.)

### 1. Barrier Free (411)

#### 2. Partially Accessible (494)

- a) Worship area (577)
- b) Fellowship areas (542)
- c) Classrooms (448)
- d) Restrooms (491)
- e) Pulpit area (112)
- f) Main entrance (514)

Letters are welcome in keeping with the purpose of *Breaking Barriers*. They may be edited for style and length.

—Rev. James Vanderlaan

## Caregivers!

Using the following web community address, caregivers can ask and answer questions or make comments that they feel could benefit someone.

[www.caregiver.guidedvision.com](http://www.caregiver.guidedvision.com)

Please try it out and let us know what you think.

—JV

### 3. Signing for the deaf (46)

- a) All services/programs (4)
- b) When requested (57)

### 4. Aids for hard of hearing and deaf (432)

- a) Special hearing aids (386)
- b) Captioned video screening (29)
- c) Printed texts of the sermons (58)
- d) Other—Power Point presentations, overheads, sermon outlines, sound system and loops, wireless hearing aids, audio- and video-tapes (44)

### 5. Aids for the visually impaired (409)

- a) Large-print bulletins (217)
- b) Large-print songbooks (345)
- c) Large-print Bibles (290)
- d) Braille when requested (26)

### 6. Special Programs (226)

- a) Friendship classes (197)
- b) Fellowship activities (115)
- c) Christian housing assistance (29)
- d) Respite care (23)
- e) Other—care to shut-ins, one-on-one assistance for children with mental impairments, special programs as needed, GEMS counseling, ADD education, children's school for children with autism and mental impairments, support network for special needs children, and others (24)

### 7. Transportation (300)

- a) In a lift-equipped church vehicle (20)
- b) In an ordinary church owned vehicle (72)
- c) In a privately owned vehicle (326)
- d) Weekly (196)
- e) When requested (263)

### 8. Participation of members with disabilities serving in staff or volunteer positions in the congregation (284)

- a) Paid staff (23)
- b) Officebearer (66)
- c) Church school teacher (51)
- d) Usher/greeter (174)
- e) Committee member (149)
- f) Other—classroom attendant, Friendship staff, choir, sound booth operator, and others (130)

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## Ingrid

**J**eanette Ingrid Vander Woude was born on Friday, December 4, 1959, in La Jolla, California. She was the youngest of ten children. Her first name comes from her Aunt Jane, but her mom loved the name Ingrid, so she goes by her middle name. Ingrid was baptized on December 20, 1959, by Rev. Roorda.

When Ingrid was asked how many nieces and nephews she had, she laughed and said it was the same number as her age: 41! She also has 54 great-nieces and nephews. What a huge family!

California Avenue School welcomed Ingrid when she was eight years old, and then she went to Sierra Vista High. At graduation, her whole family came, and then she went to Disneyland.

Ingrid has worked for fifteen years at Green Thumb Nursery. She works three mornings a week and cares for the plants. She has been Employee of the Month.

Around the house Ingrid is responsible for the plants and birds (cockatiels). She prepares some meals for the family, and has been known to order beautiful cakes to celebrate special occasions.

For fun Ingrid loves to create things in her very own wood workshop. This love of woodworking must have rubbed off from her dad.

Flying to Idaho to visit her sister Tracy is a lot of fun. Aunt Jane is fun to play ping-pong with, and Sjoelen is

fun with Ray and Edna, Jack and Jane, and her mom and dad. Ingrid also loves to play UNO and other card games. Country-western and Christian music are Ingrid's favorites. She also loves to go out to eat.

Ingrid publicly professed her faith on January 15, 1984, along with Lisa de Jong (Luurtsema) and Jack (Rita) Brouwer. Rev. Howerzyl asked Ingrid if she loved the Lord, and even though she was very nervous, she answered, "Yes!" Her mom was so happy for Ingrid, she cried tears of joy! The whole church was happy for Ingrid.

Now Ingrid has a one-on-one Bible study with Grace Brouwer during Sunday school time. They've been doing this for four years. They enjoy their Bible Study time together. Ingrid's favorite songs are "This is My Father's World" and "Kum Ba Yah." Signing "Jesus Loves Me" is fun too, and Ingrid would love to be in a choir someday. She loves the Bible stories from her very own Bible.

Ingrid loves to greet and help people. She loves to laugh and have a good time. Most of all, Ingrid loves the Lord.

*Grace Brouwer*

*Grace lives in Escondido, California, and has written for BB about her son John, who has Down Syndrome.*

## A Stutter

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some detached and distant being at the front of the classroom, they recognize that I am a real person with struggles just like them! A valuable spin-off of this activity is that sharing of myself encourages them to open up about themselves and their struggles.

Second, I decided to do all I could to help others who stutter. Besides becoming involved in leading the local stuttering support group, I have given several public presentations on stuttering, written several articles on the subject, and serve on the board of directors for the British Columbia Association of People Who Stutter.

Third, I decided to deliberately do things I would ordinarily avoid. This is not to say the battle is over. I still slip into avoidance behaviors, and I still have bad speech days. With God's help, though, I'm seeing more and more how God has strengthened my character and has given me unique opportunities to serve him. My attitude toward my stuttering is changing from "Why me, Lord?" to "How can I use this to honor you and serve others, Lord and ease the suffering of other stutterers?"

*Jack Beekma  
Prince George, BC*

Stuttering may look like an easy problem that can be solved with some simple advice, but for many adults it is a chronic, lifelong disorder. Here are some ways that you, the listener, can help:

- Refrain from making remarks like "Slow down," "Take a breath", or "Relax." Such simplistic advice is demeaning and is not helpful.
- Let the person know by your manner and actions that you are listening to what he/she says, not how they says it.
- Maintain natural eye contact and wait patiently and naturally until the person is finished.
- You may be tempted to finish sentences or fill in words. Try not to do this.
- Use a relatively relaxed rate in your own conversational speech—but not so slow as to sound unnatural. This promotes good communication no matter with whom you are speaking.
- Be aware that those who stutter usually have more trouble controlling their speech on the telephone. Please be extra patient in this situation. If you pick up the phone and hear nothing, be sure it is not a person who stutters trying to initiate the conversation before you hang up.

*—from the pamphlet "How to react when speaking with someone who stutters" by the Stuttering Foundation*

# Holly



**H**olly was born on June 8, 1981. She came to live with us when she was nine days old, originally as a foster child. Holly was born with Pierre Robin Syndrome. That means she was born with an underdeveloped chin and open cleft palate. This syndrome is very rare. She was also born with Cerebral Palsy, brain damage, and autism, though this was not discovered until she grew older. Her birth weight was 4 lbs, 4oz. The doctors did not offer us much promise. They said she probably would never walk or talk and that her life expectancy was no more than a year.

When Holly had been with us only five days she had to be returned to the hospital. Our family usually would get together every Sunday at my older daughter's house. She lived about 40 miles away at the time. On this particular Sunday the whole family was concerned about Holly. Her color was so gray, and it seemed as though she was constantly gasping for air. We were concerned that she would not last through the weekend. This was all so new to us that we probably didn't realize the severity of the situation.

We took her back to the hospital and were told that she was in severe respiratory distress. Because of all her problems she wouldn't eat, so they put a little tube into her nose—called Gavage feeding—which Holly did not like at all. This was our first sign that Holly was going to fight for her life with everything she had. It wasn't until two years later that Holly came home to stay. She was in hospitals all that time, and I visited her every day.

Here are some notes I wrote down in a journal during that time:

July 6, 1981 Holly is put on an alarm blanket. Every time she stops breathing the alarm goes off. She is one month old.

August 27, 1981 Holly now weighs 6 lbs, 12 oz. For the first time

she smiled when she heard my voice. I'm still concerned about her mental state.

November 12, 1981 Holly has been back to Children's Hospital. She is very weak. The doctors say that a gastrostomy tube should be placed in her stomach so she can absorb more of the nutrients in her food. She still can't eat. To help her breathe better they inserted a tracheotomy tube in her throat. She can finally sleep on her back now. The doctors say it will take another six to eight weeks before she can go home. I'm tired of driving the freeway.

December 15, 1981 Holly had a gastrectomy done to correct the valve problem in her stomach. She was doing very well until Saturday when the hospital called to say that she had to go back into surgery. She has developed an infection. She was placed in what they call "open basket" because her body temperature was dropping. She was in bad shape. Her weight is slowly going downhill.

December 18, 1981 Holly is doing great today. All the IV's and broviacs were disconnected. She is on her own now.

December 22, 1981 Holly has been moved back to El Rancho Rehab. She has been here one week. We hope to take her home for a little while.

December 29, 1981 Holly is home with all her machines. She is in our bedroom. It is difficult for me with the trachea tube because she can't swallow. We need to suction her as much as possible and she has a lot of mucous.

January 3, 1982 Holly is back in the hospital gasping for air. The trachea tube went dry, so they put her in a mist tent.

January 5, 1982 Holly is put in the intensive care unit until January 16.

January 17, 1982 The doctors feel they should put her on a 24 hours feeding. The machine is like an IV

pump. It monitors her intake and dispenses it over a 24-hour day. She is still losing weight.

January 20, 1982 I was at the hospital and knew something was wrong. Her GT tube had been clogged. No food was going through. Still losing weight.

May 6, 1982 Holly weighs 14 lbs, 12oz. During the second week in May she was transferred

back to Children's Hospital with another case of pneumonia.

June 8, 1982 Hurrah! We are celebrating her first birthday today at the hospital. The GT feeding is now scheduled for 6:00 p.m. to 6:00 a.m.

June 29, 1982 Outcome of her head CT scan just as we suspected: brain damage.

July 9, 1982 Holly has her first seizure during her sleep. She comes home on a pass. Some good news, the doctors say that her lungs are developing well but she still needs to be on monitor.

July 11, 1982 Holly has been travelling between Children's Hospital and El Rancho Rehab. Along with all the other problems, she has had six mastoidectomies (ear surgery). Her ears were always draining. On the fifth procedure the doctors found a hole in her skull with part of her brain protruding. Two neurosurgeons were called in to push the brain back in and close it with mesh. This took care of the draining. With the sixth





operation they inserted a manmade ear drum.

December 27, 1982 The court gave us full custody of Holly and we had her baptized at Rehoboth Christian Reformed Church. This was a very happy day.

For two years I had slept next to Holly's bed. She needed to be suctioned all the time during the night. One night it was 33 times that I had to suction her. So back to the hospital. But the times at home between hospital visits were becoming much longer. In 1992 we took Holly to Primary Children's Hospital in Utah. There they took out the trachea tube. The doctors were very nervous, and so was I. But it all worked out well. She stayed in the ICU for five days.

We worked slowly with Holly to exercise her legs. We wanted to see if we could get her to crawl, and she did. Over the years we became much more comfortable with all the machines, and now she only has her feeding machine. With her inability to swallow her esophagus collapsed as well.

Today Holly is twenty-one years old. Everyone in our church accepts her. During the day she goes to a special school. The school picks her up at 9:00 and brings her home at 3:00. Holly is a very happy young lady, always smiling. Even though she can't talk, she seems to express her desire very well. For instance, if there is something she does not like on TV she will bring you the remote control. At age 11 she got rid of her

wheelchair and started walking, between us first, and then on her own. She does little things around the house like getting my slippers. It took a whole year of working with her, but she finally got it. Her Cerebral Palsy is not getting worse, and her autism shows only by her head rocking and by her hand flapping.

We love Holly very much and firmly believe that the Lord put her in our home. God has chosen us to be her parents and we are very thankful to him for this.

*Mary Van Vliet  
Mary is Holly's mother.*

*The Van Vliets now live in Twin Falls, ID to be near their children.*

## Alone

Last week I went to a workshop entitled "Dancing with Partners or Why Do My Feet Hurt?" It was a quirky title, and as I prepared to go I thought, "What does this have to do with children who have special needs?" It turned out to be a very good workshop—a sort of guide for parents of children who have special needs on how to understand and cooperate with the agencies or "partners" we work with—although I wasn't sure of that until afterwards. During the three-hour presentation I kept thinking, "But what does this have to do with me?"

The presenter, Janice Fialkna, MSW, ACSW, is a mother of a special needs son who is eighteen years old, and she was speaking as a mother as well as a professional. One of the things I learned that day was how differently birth mothers of special needs children feel from those of us who adopt them. There are so many emotions birth parents go through—anger, denial, frustration, depression, disappointment—that we who adopt do not feel. These parents didn't have a choice; no one asked them if they wanted to take this difficult journey. I, however, made a choice; and although on occasions I experience some of the emotions and feelings these parents do, I'm sure it is never to the same degree.

As I thought about this, I thought about my choice to adopt Alexandria, who is significantly and severely impaired. I love her so dearly, and she is the joy of my life. I thought about how much she has changed our life for the better, even if we do struggle.

There is one thing I know I have in common with the birth parents of children who have special needs. It is the feeling of being isolated and deeply alone. I read once that the feelings with death and the feelings with love are emotions with the same depth. Love is as strong as death. I love Alexandria so much that I know what they are talking about.

Yesterday Alexandria, who will be five years old in December and weighs 33 pounds, entered Mary Free Bed Hospital in Grand Rapids, Michigan, for a trial run, hopefully to have a baclofen pump implanted in the near future. This would take away the spasticity that significantly tightens up her small body. Yesterday's procedure was invasive. A test dose of baclofen was injected into her spine so that a physical therapist could test her responses over the next eight hours.

Things did not go well from the start. We arrived in the hospital at 6:00 a.m. and got settled in. But when they looked for a vein to take the I.V., she had one lone vein and it was iffy. So we had to wait for the anesthesiologist. He got the I.V. started after two significant pokes, pulls and prods, and then began the procedure. Next, he could not quite get the needle into Alexandria's spine. Again three significant pokes, pulls and prods, and then he got it. Meanwhile she received more anesthesia. And thus the problem that made this particular day one of the worst days of my life.

*continued on page 8*

## Lazy and Dumb, or Learning Disability?

"So, kids, how was church school tonight?"

**Kid 1:** "Mom, I am not going to catechism anymore! I am sick of feeling stupid!"

**Kid 2:** "My teacher is cool, so I'll go back, but I'm not answering any questions in class!"

**A**s a parent, you hope the answers to your question will give you insights into how much your children are learning about faith in Christ and his church. But often on the drive home, what I get is how frustrated my children feel. Sometimes it's the teacher, sometimes it's the material or the way it's presented, sometimes it's the other kids and sometimes, after dealing with it all day, it's just the last thing they want to deal with again at church. So what is this thing my kids deal with? It's a learning disability.

My message to church leaders is this: "That kid in your church school class who is driving you crazy might not be lazy and dumb, or even a discipline problem. What he might be is a child with a learning disability." One in ten people have a learning disability, and a learning disability is not a lack of intelligence or motivation. Learning disabilities are often called "hidden disabilities" because you can't tell a child has one just by looking at him. In fact, to have a learning disability properly diagnosed, a person must be tested by a professional, usually a psychologist.

The tests begin with measuring IQ. A person's IQ must be in the average, above average, or gifted category to be considered as having a learning disability. But performance in other areas such as reading, writing, or math will be significantly less than what you would expect given their intelligence. If you remember only one thing about learning disabilities, I hope it is that people with learning disabilities are not dumb; they can be geniuses like Albert Einstein or Leonardo da Vinci, both of whom had learning disabilities.

A learning disability is a difference in the way the brain perceives, interprets, processes, or retains information. Most of the time this means the person with a learning disability will take longer on certain tasks or need more repetition. For example, Matthew, a young man I work with, has difficulty decoding new words because he doesn't readily connect the sound of a letter with its appearance. He has first to identify the letter by its name. "That is the letter D." Then he must match the name to the sound. "D makes a da sound, the word begins with da." Because of this extra step, it takes Matthew longer to sound out a new word. Imagine how he feels when it is his turn to read a passage in the Bible out loud.

Children with learning disabilities experience the same difficulties in church school that they do in their regular school. But in church they usually do not have the same

staff support or understanding. For example, both of my children have laptop computers in school to use in all their classes, but not in the church school.

The frustration children with learning disabilities have often spills out in negative behaviors. The child who is refusing to read or to show you his church school assignment may not be a difficult child, but rather may be trying to avoid humiliation and embarrassment. Sometimes it's not the child who needs to change, but the presentation or the environment.

What can church leaders do to help children with learning disabilities? Here are three suggestions to get you started:

1. First, be sure that your church is accessible to all people with disabilities, including learning disabilities. There is a website with an interesting trio of pages on accessibility, including a checklist you can use to see if your church is open to people with disabilities. <http://www.uua.org/faithinaction/jtwacc/access1.html>
2. Continue by building awareness. Offer information to your teachers and youth group leaders about what learning disabilities are and how to help children thrive and succeed in the church community. You might offer workshops lead by professionals in the field of special education or by personnel from your local Learning Disabilities Association. LDOnline, a Learning Disabilities Information website, has a section called "Helping the Helper" that has excellent tips for volunteers working with children with learning disabilities. <http://www.ldonline.org/helpinghelpers/>
3. Finally, talk to adults and children with learning disabilities and their families to find out what your church community can do specifically to help them become more active.

My children are still in church school, although I don't give them a hard time if they need a break from it. My son loves Cadets and my daughter is a Counselor in Training for GEMS. My church's leaders are supportive. However, I do meet people who are not as fortunate, who have been deeply hurt, who are in need of support and comfort, who feel separated from God because of their learning disabilities and because of the reactions of others. We need to recognize the barriers that exist for children and adults with learning disabilities and encourage their full participation in worship and in the church community.

*Irene Ouellette  
Irene is the Learning Strategist/Assistive Technologist for  
St. Clair College, Thames Campus, working with post-  
secondary students with learning disabilities. She is a  
member of Grace Christian Reformed Church in  
Chatham, Ontario.*

### Pray for us constantly.

**M**ay we gripe? Are we allowed to complain? I think so, if we do not make it a habit, OK?

Today is my turn and I think I have a beef that many permanently disabled people and their families share with me.

In most church services there is a time for congregational prayer. This is an opportunity to bring before the throne of our heavenly Father all our joys, concerns, and wishes. We pray for our land and the leaders placed over us; we pray for war-torn countries; we pray for those people who are suffering from famine, earthquake, or other calamity. We pray for little Johnny who fell off his bike this week and broke his leg. We pray for safe travel for the Vandutch family who are going to spend their vacation in Florida.

And we pray for the sick and shut-ins. Just that, the "sick and shut-ins." Sometimes we even get very specific about a person recently in the hospital for whatever reason. This prayer for the particular person will be repeated for several weeks or until the crisis is largely over. And after a while we hear nothing any more. Then there are the prayers of thanks for good things, like healing, or a job for an unemployed member, or a successful youth event. All good things, things that need to be talked over with God. But there is an issue that I think needs to be handled in a better way.

We have in our congregations people who are permanently disabled, usually stressed because of their situation, often unemployed, mostly sick, very much broken and otherwise in need of constant prayer. But what happens in most churches? When a crisis strikes a person or family, their need is brought before the Lord several times, they are mentioned by name perhaps even for a whole month, but then the prayer

concern seems to wane. Soon there is no more mention of their plight. Now they are relegated to the category of "the sick, shut-in, and needy." Or even a generic "those who are in need of prayer." While little Johnny Smith has a broken leg that will heal in six weeks, and in the meantime he has a wonderful colored cast that makes him the envy of his classmates. Yes, I know he also needs our prayers and concerns.

What of the one who is permanently disabled, who is in a wheelchair or confined to a bed? What about Mary who has constantly suffered from a debilitating depression for years now? What about the family with a child who suffers from an incurable neurological disease? What about brother Vanklomp who is afflicted with Alzheimer's disease?

What about his wife? These are situations that are with us every week, every Sunday, but because the conditions go on for many months or years the impact or prominence of these situations seem to diminish over time. We pray for the "sick and shut-ins." "Lord, please be with them." Wow! How impersonal can we get? Has our compassion been depleted of words? Don't we know what to pray for anymore? Have we lost our confidence in our prayers when the answers we seek are not forthcoming?

Please, pastors or service leaders, can we not find a better, more personal way to include these situations

in our congregational prayers? Those who have long-term needs also require our constant attention and long to be brought before God's throne in prayer. Their daily lives are ever in need of God's healing and grace. Without ongoing prayer support their lives would be very difficult indeed.

I realize that a long litany of the same old concerns soon becomes unwieldy and perhaps even a little boring. Perhaps all these ongoing needs can be highlighted on a monthly basis on a designated monthly Sunday. At the least all those who have ongoing needs and require our communal as well as corporate prayers can be named in the Sunday bulletin or newsletter.

Permanent disabilities and ongoing illnesses often become so commonplace in our church families that we forget the crisis is permanent and ongoing. Until Jesus returns and makes all things new we will have these with us.

Please, pastors and leaders, find a way to include these in your congregational prayers and to commend them for individual prayers.

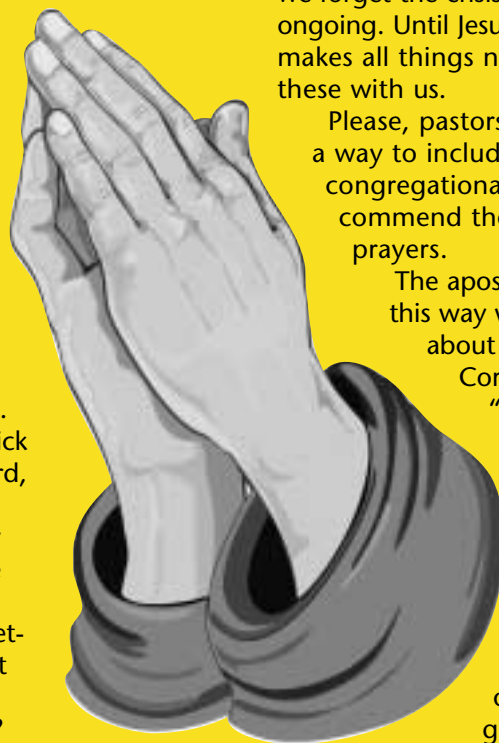
The apostle Paul puts it this way when he speaks about praying to the Corinthian church:

"On him we have set our hope that he will continue to deliver us, as you help us by your prayers.

Then many will give thanks on our behalf for the gracious favor

granted us in answer to the prayers of many" (2 Cor. 1:10-11).

*Bert Zwiers  
Bert is a former member of Disability  
Concerns of Eastern Canada and  
has Multiple Sclerosis.*



Alexandria was supposed to have been in a "twilight" sleep and should have awakened anywhere from twenty to sixty minutes after the procedure. My daughter "slept" for six hours. As the time slowly passed, I watched as the doctors and nurses kept coming in to check on her. I watched as their words said one thing but their body language said another. And I knew that my baby girl wasn't doing well. Her vitals were all good. But she was still what they called "under." Around noon they decided to administer a drug to reverse the affects of the anesthesia. She jolted, but still did not awaken.

I was scared, and alone. No one called the hospital to see how she or I was doing, even though lots of folks knew we were there. The couple calls I made from the hospital either got the answering machine or people who, it seemed, didn't really care. Their days were full and they just wanted to get on with their busy lives. Lots of thoughts go through one's mind in a time like this. I kept thinking about what someone told me last year when Alexandria was admitted to ICU and I found myself in the same situation. She said to me, "Well Cindy, you knew what you were getting into when you decided to adopt special needs children." And as I thought about that statement, I felt even more isolated and alone. Did I really know what I was getting into? Yes, I did make a choice. But this is my little girl lying here. My little girl not of my flesh but of my heart and my soul. A special precious gift that God entrusted to me.

Around 1:00 I did the only thing I knew to do. I opened my Bible. And there was my favorite verse: "'I know the plans I have for you,' declares the Lord. 'Plans to prosper

you and not to harm you. Plans for a hope and a future.'" I closed my eyes, and as I finally allowed the silent tears to stream down, I prayed. And I told the only One who seemed to care how alone and afraid I felt. When I finished praying I picked up the phone and called my partner in life and the father of my child, and said, "I need you."

Alexandria finally started arousing after 2:00 that afternoon. Everyone was so relieved. We were able to go home at 6:30 that evening, exhausted but relieved that things turned out okay. Alexandria will not be getting a baclofen pump. We don't know what made her stay under so long.

My main reason for writing this is to share with the church and with fellow Christians part of the journey parents of a child with disabilities travel. This is only a small piece. My question for the church is, What is your duty (at least that's how Malachi puts it in the Bible) when there is a family in your church with special needs? How do you minister to that family? Is Christ there? Are we as a church being Christ for those who often feel alone and isolated? Or do we say, "You knew what you were getting into"? Or, "What does this have to do with me?"

Another thing I read yesterday in that hospital room was this: "Our problems are like shadows that reveal the Son behind the clouds." Oftentimes God also uses his people to reveal his Son.



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