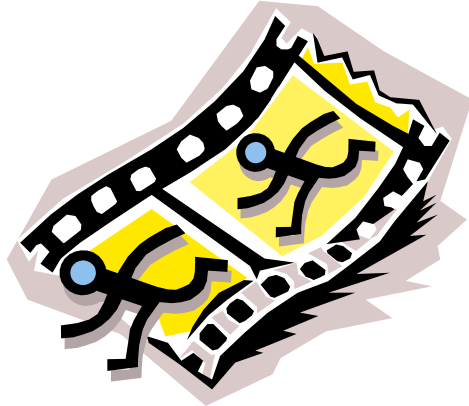


The People First Connection

The Voice of Self-Advocacy in Oregon

Published by Self Advocates As Leaders



The Power of Stories

We are going to the movies for this issue. You will read a story of a reunion and the words of a film maker. You will read about the friends, work and lives of people who experience disabilities. Each person sees the world in a different way. When you share your story, we get to learn from you. And you never know, you may learn something about yourself!

**We want to
hear from you!
Send us a story!**

Voices in Oregon are
getting stronger.
Be a part of it.

Our Address:

c/o Marcie Tafalla

PSU-RRI

PO Box 751

Portland OR 97207

www.asksaal.org



One Family Reunited Gives Hope to Many Others!

**By Judy Cunio, Self-Advocacy Coordinator
Oregon Council on Developmental Disabilities**

This is a true story about a brother and sister named Jeff and Molly who were separated for almost 50 years.

When Jeff was about 6 years old, 3-year-old Molly disappeared. When he

asked his parents "where's Molly?" he was told to forget about her and to never talk about her again. His mother told him that if he ever tried to find Molly, he would be cut out of the family.

Jeff always wondered what happened to his little sister. But as time went on memories began to fade. Jeff grew up to be a very successful filmmaker. Jeff's accomplishments include working for KATU, CBS, CNN and ESPN.

Molly led a very different kind life than Jeff did, because she lived at Fairview Hospital and Training Center, as it was known back then. Molly never knew she had a brother, or any family for that matter. Jeff and Molly lived in two very different worlds and never knew that someday they would come together.

If things are supposed to happen, they will.

In 2003, both of Jeff's parents died. When he went through his father's wallet, he found a piece of paper with Molly's name and social security number. In a closet, he found a folder with information about Molly and found out that Molly had been put into Fairview those many years ago. Jeff also learned that his father secretly did everything he could to stay in contact with Molly – even after he was told by Fairview staff to stop visiting her because she became upset when he left. He even formed a clown group that would go entertain the people at Fairview and no one ever knew that he was one of the clowns.

After 47 years of Jeff and Molly being apart, it only took 3 phone calls to find each other again. When Jeff and Molly first reunited, Molly was able to say just a few words and did not have

very many social skills. But in the past three years they have had a lot of time together and Molly has developed many more skills and language.

The past 3 years for Jeff and Molly have been a time of getting to know each other and making up for lost time. They do many things together as a family.

If this were the end of the story, it would be a very nice story. But that's not the end. Soon after Jeff found Molly, his wife Cindy learned that her brother-in-law had a sister. His sister also had been sent to Fairview. It took several months to find her. Jeff knew that there had to be thousands of people in the same situation, and he wanted to help make it easier for other families to find their lost loved ones.

In 2005, the Daly family celebrated when what is now known as "Molly's Bill" passed into law by the Oregon Legislature. Senator Peter Courtney sponsored the bill. This law says that if a family member is looking for a lost loved one who used to live at Fairview or another institution, they can call the Department of Human Services. Someone from the Department will contact the person with disabilities and let them know that a family member is looking for them and leave it up to the person with disabilities if they want to make contact or not.



The Daly family is hoping similar laws are passed in other states across the country. They got The Arc of the United States to set up a website (www.findfamilyregistry.org) to help families reconnect. They have also made a movie called "Where's Molly", a documentary about their journey to finding the way back to each other and how both of their lives have changed for the better.

This story is a story of hope and encouragement and shows that happy endings really do happen.

Want to see the movie? For information, contact: www.wheresmolly.net



Beyond an Institution

By Sally Kramer, Portland

I am 54 years old. I am originally from Louisiana, from a little town called Bunkie. When I was born, I was diagnosed with cerebral palsy. Doctors told my parents that I would never walk or be able to do anything for myself. Boy, were they wrong!

I have a brother, Bill, who lived in Portland and he is the reason I am here today. Before that, I was living in an in-

stitution in Alexandria, Louisiana from six years of age until I was 21. I had friends. I only got to see my mom three weeks out of the month. My brother went to Louisiana Tech and my sisters went to Louisiana College at that time.

Now, I am married and our anniversary is the 18th of June. We have been married 13 years! So, you can see where God can put you if you are really into it.

I am working and supporting my husband and myself. Hopefully, in a few weeks he will be able to get a job. Now, I am working with SAAL and trying to learn other responsibilities.

I have a niece that is going to have a bone marrow transplant. **It is supposed to be on the 18th of June, the same day as our anniversary. Her brother is going to be the donor.** I am hoping the doctors are wrong about her diagnosis because she is only six years old. She turns seven on October 9th. She doesn't walk or speak. She has a website: <http://prayforcaroline.com>. Her smile gets her anything she wants! I have a special connection and love for her. Her mother is trying to be very helpful. Caroline has an older sister, Mary Grace, who turns 10 in December. Matthew, the donor, turns three in July. I love my family very much.

Follow-up note: Caroline was too ill to have the surgery yet. I will be spending time with her in the next month. Doctors are positive about what surgery can do for her.

A Piece of My Heart

By Michael Park, Portland

There are souls in this world,
Souls without love or heart--
Souls that have been forgotten
By those they have loved.

Forgotten memories are all they have--
Love is hard to find; pleasure easy,
It will last only a minute or two--
Forgotten love is all they have.

And forgotten souls we will become
Like that soul in the corner
Of that street, a lost soul,
Dying of hunger and heartbreak.

But I am gratified and satisfied--
For I had you and your love--
Knowing I will not be forgotten,
For you took a piece of my heart.



Life Stories Workshops

Cottage Grove:
Coming this Fall

Monmouth area, plan
ahead: MLK Jr. Day,
January 21, 2008

A Hobby Pays for Itself

By Chris Schleiger, Toledo

I have a hobby and that hobby is RVs (Recreational Vehicles.) I bought my first RV from a high school teacher. I sold that one and bought my second RV from a close family friend. We used the RV for four years of camping at various camp-grounds. It was getting worn out and I decided to look for another RV. I found a travel trailer that we liked, so I sold my RV to help pay for the travel trailer. My parents are helping to pay for the travel trailer and helping me to save to buy a new travel trailer.

I am interested in designing RVs for different types of people. The one family I am interested in designing RVs for is the Roloff family. Matt and Amy Roloff live in Oregon. They have a reality show on the learning channel called "Little People, Big World." I would like to talk to them and get ideas on what they think would help them to camp in an RV.

I have read many books on how to set up, repair, and live in RVs. I have studied up on towing, hooking, and unhooking the RV and now I would like to learn more about design. I am interested in designing (inside and outside) for the four basic types of recreational vehicles. The four basic ones are motor homes, travel trailers, fifth wheels, and campers.

My goal is to meet Matt and Amy Roloff. I am a huge fan of **them**. I would like the chance to learn from them.





Impact!

By Benjamin Snow, Colorado

It's easy for young people to think that the world is such a big place that they don't have the ability to change it. There might be some issues in the world that affect a person but he or she may not have the courage to speak out to society about what affects them.

In the summer of 2006 I discovered Film Your Issue, a national contest challenging young people to make a film 30 to 60 seconds long. The subject matter was to be any issue that concerned a person, something they wanted others to know about. I knew immediately what I wanted to do.

Like most people, I really enjoy watching movies. I am studying journalism right now and I plan to be a movie critic when I finish school. For a long time, I have watched movies not just to watch the story but also to pay attention to things such as camera work, editing, music, and acting.

I've noticed that in many cases, if a character in a movie has a disability, the character is often portrayed to be unfortunate, not very smart, and pretty

much have a lousy life. I have a disability, and my life is nothing like that Hollywood stereotype. The issue I decided to make a film about was Hollywood's "pity portrayal" of characters with disabilities.

I wrote and directed a film that was 60 seconds long, titled Thumbs Down To Pity. It begins by showing various clips of Hollywood movies that show pity toward characters with disabilities. Then the camera turns to me and shows the audience some of my daily life, and doing everyday things like karate and paying my bills. I ended the film with my advice to people who make Hollywood movies: "Enough with the stereotype – it's worn out!"

The Film Your Issue contest was sponsored by USA Today, Toshiba and the MSNBC cable channel. There were many well-known people who served as contest judges, such as Walter Cronkite, Brian Williams, Senator Barack Obama, and actor George Clooney.

There were over 330 entries submitted for review. For the first round of judging, 35 films were selected as semifinalists to go on to a week of public voting on the MSNBC web site. My film was selected as a semifinalist, and it was also later judged as one of the five national winners. The other winning films included one about AIDS protection, two on hunger in Africa, and a film about the importance of having a conversation in our everyday lives.

Winners were flown to New York City for an awards ceremony. I arrived a few days early to do a little bit of sight-seeing. I went to world-famous places like Central Park, Times Square, and Rockefeller Center.

About 200 people attended the awards ceremony at United Nations headquarters. I had the chance to talk with journalist Judy Woodruff and actress Ellen Burstyn, who had both been contest judges.

The five winning films were introduced and presented to the audience. Each filmmaker then gave acceptance remarks and briefly talked about their reasons for making their film. When it was my turn to talk, I felt like I had been given an Academy Award.

It felt very exciting and gratifying to think that the message that I tried to communicate in my film was appreciated by so many distinguished people. Many people congratulated me on my film and mentioned that it was an important message that they had never really thought much about.

I felt like I had been successful at doing something that had a positive impact on the world.

I feel like I learned many important lessons during my Film Your Issue experience. For me, the actual making of my film was a new and interesting experience. I had fun working with a camera and I found myself laughing at times because of technical problems like shadows and motorcycle noise in the background. I learned a little about what camera angles worked best for the audience to see something clearly. And I saw how with the technology of editing you could rearrange the order of things. It was very hard work, but it was also fun.

The contest provides young people with the opportunity to share their opinion with a very large audience, and that's unusual. It was important for me

to be as honest as possible and say what I really meant. Since I only had 60 seconds to give my message, I had to think about it a lot and plan what I wanted to say.

After my film won and was presented in so many situations, I found out that there was no way of knowing in advance about all of the different ways that my film could impact me personally. For me, speaking up about an issue I care about has turned out to have a great impact on my education and career plans.

At the United Nations ceremony, I met Dr. Larry Long, a professor at Illinois State University, who was extremely interested in my work. He talked specifically about possibly having me attend the school there when I complete my community college studies.

I also had the chance to meet Craig Moon, the publisher of the USA Today newspaper. I gave him my business card and told him I would like to contact him about maybe working there when I finish college.



Another result of the awareness of my film is that I have gotten numerous invitations to speak at organizations. Several universities and government agencies have requested copies of my film for their future education and training purposes.

When I entered Film Your Issue, I had no idea that people all over the world would be watching me pay my own bills, or even that there would be famous individuals on the judging team. It has been one of the best things that ever happened to me.

I think I have found that when you take action and get involved in something that is important to you, as Humphrey Bogart famously said in Casablanca, "I think this is the beginning of a beautiful friendship."

A Friend Who Needed Me

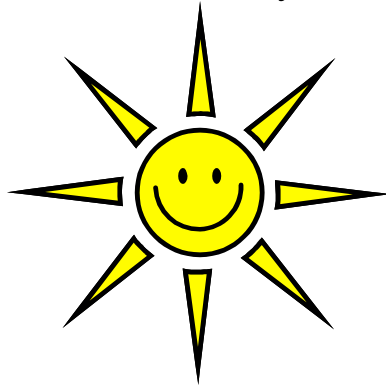
By Ashley Rose Johnson, The Dalles

I have a friend who was having problems. When I called him one evening I could tell something was wrong, so I helped to calm him down. My friend has helped me a lot of times when I had a lot of problems of my own.

I remember when I got in a bicycle wreck. He was very worried about me because I did not show up at his house. I was going to go to the parade with him. It did not happen that morning because I was in the emergency room. I could not walk on my left knee and had to use crutches. He called everywhere to find me when I did not show up.

My friend is very supportive of me and was caring about me being hurt. This goes out to thank my friend for visiting me when I was hurt and for fun times we've had.

Take time to appreciate the friends you care about dearly!



Success!

By Theresa White, Aloha

I have struggled with weight problems off and on throughout my life. We've tried different weight programs with no success. I am now on a

different program, but I've been there nearly 8 months and I haven't lost very much weight. Frustrating! Allie, Tammy and my mom are trying to help me but I haven't been listening to them. I have decided to start listening better to what they say.

I've had a problem with cola, I was drinking 5 to 6 cans a day. That's bad. Now I'm trying to drink 1 or 2 a day. I'm trying Allie's idea of putting seltzer water into my cola.



I'm trying very hard now, I'm

not going to give up. Someday I hope to be at my goal weight – I know I can make it with support. I hope to lose a little before I see my brother Kevin. He loves me and he's worried about my weight.

Bullied as a Child

By Daniel McKinney,
Newport

I would like to share with other people who have bully problems in their life. I don't want to see anyone in the community get hurt.

I remember one time I went up to a group of kids. I wanted to share something with them. One of them was inconsiderate and did not want to play with me. So they were being cruel and rude and I had to make a choice of what to do. I backed off.



While I was growing up, older kids bullied me the most. I learned my lesson to keep away from some kids, so they couldn't make fun or push me around. I had to

remember, in this world, many children get hurt. Sometimes they had abusive parents who taught them to do cruel things to other kids. In middle school, Bobby, the son of my mom's best friend bullied me. He embarrassed and intimidated me in public. He said things to hurt me and I did not appreciate that. He used a prank to fool other kids to tell them a humorous joke from my past.

I needed help before I went to high school, so I would not be bullied. I had a friend who came from a private school. He would jump on the bullies and he became my bodyguard, who protected me. I also met a kid in Latin and physical education (P.E.) in eighth grade. We did nice things for each other, went out to the movies, had birthday parties and went out to lunch or dinner. He became my hero who rescued me from trouble. He and I were tired of being bullied. Michael and I both graduated from Niceville Senior High School around 1997.

Accepting the problem of bullying helps. Then you can be resolved and can move on with your own life. It helps to embrace the past to be stronger in the present. The right thing to do is to stand up to these problems. And bullies should be disciplined.

My advice to keep away from bullies is this:

- ✓ Don't give them a chance to ask inappropriate questions. Don't get into a discussion with them.
- ✓ Don't make eye contact; don't look at them.
- ✓ Move out of the way of a bully. You can walk away.

Bullies are prejudiced.
They scare people and build fear in communities.
Everyone in the community needs support. It helps to get encouragement from other victims. Remember this, you need to act with integrity.

Independent Dreamer

**Kristin Nichols,
Lincoln City**

My name is Kristin Nichols. I was born, raised, grew up and lived in Colorado for over 36 years.

I am an independent person. I had my own apartment for over six and a half years. When I was 16 or 17, I started going places on my own. I sometimes go get coffee. I took buses to the movies and to the shopping mall.

I love to learn things by traveling. I am a world traveler. I learn a lot when my parents and I travel. We have been to England, Scotland, Italy, France, Switzerland, Mexico, the Caribbean, Brazil, Peru, Canada, Roatan (Honduras), and all over the United States.



I have snorkeled. I swam with stingrays and dolphins. I kayaked down a real jungle river. We went to the Amazon rainforest in Brazil and explored Machu Picchu in Peru.

We traveled many times to Oregon. **I had a dream to live near the ocean. Now, at the age of 37 years old, I'm living near the ocean in Lincoln City, Oregon – and loving it! I am really happy.** It was really hard to move and leave my friends. I love going out to places with friends. I love making new friends.

In time, I will have my own apartment and I would like it to be in Newport. Right now, I'm very happy living with my parents and having fun.

New Website

Visit the Oregon
ADA Center for info
on the Americans
with Disabilities Act
(ADA)

www.oregonadacenter.org

ADA Policy at the Oregon State Fair A Notice For Readers Mark Knecht, Salem

The Oregon State Fair will have the following policy regarding admissions for visitors with disabilities. The policy will start at the 2007 Fair.

1. If a visitor needs an attendant to navigate and enjoy the fair, the visitor will pay the regular admission price and the attendant will be admitted at no charge.

2. Agencies that assist persons with disabilities will be eligible for group discounts. They should purchase their tickets through regular ticket outlet channels. The Oregon State Fair will reimburse the agency for tickets they do not use.

If you have questions, contact Bev Young with the Oregon Parks and Recreation Department 503-947-3244.



“Ask Saaly”

Has the Oregon Health Plan denied you?

I was denied physical therapy when I injured my left knee last August. I need to find a way to respond to them for denying it. My knee will not be strong enough to compete in this year's track and field events. I have written to OHP and requested a court hearing.

If anyone has good advice for me, please contact me through Marcie Alvarez, PSU-RRI, P.O. Box 751 Portland, Oregon 97207. Ashley Johnson, The Dalles

NEXT Question:

What is Self-Determination?

My Life

By Russell Neuman,
Corvallis

I was born in July 1989, in Philomath, Oregon. I had begun to bab-

ble and say “Mama,” but I developed a high fever at 18 months. My aunt came home from Korea with lots of bad germs and gave them to me. I had never even been sick before. What had started as just a cold turned into pneumonia.

I started having seizures, fairly common with high fevers at that age. Dad's parents came to see me and said I was possessed by the devil. He told them to go home.

A few weeks later, I was ill again and had seizures every two hours, on the nose. Mom and dad took me to the emergency room; the doctors did not believe my mom that the seizures were regular. The nurse took my mom aside and told her she should demand to see a neurologist. She did, and that was the beginning of her experience as a “mother from hell.” This describes mothers who demand more help for their kids with disabilities. It is a real organization with newsletters and members.

One doctor said, “I don't do pediatric pa-

tients,” and walked away. Another doctor saw the problem and said, “I have no experience with pediatric patients, but I will help your child.” She hooked me up with a medication that made the seizures stop and we went home. I had no seizures, but I slept all the time. Mom and dad decided to take me to OHSU to see pediatric neurologists.



At OHSU, they switched me to another medication just before my sixth birthday, one that wouldn't make me sleep so much. Two weeks later, I passed out with an atonic seizure. After 18 hours unconscious in the ER, I stopped breathing entirely. When the doctors put an adult breathing tube down my throat, my throat was ripped. Mom came with me to OHSU by air ambulance. Eventually, they stopped the seizures and I could breathe. I managed to be without seizures for five years, so I stopped all anti-convulsants. I could

sit up in a chair to watch TV. I learned to do a high five, and to smile when friends or therapists read or talked to me. I even went to school in Corvallis, then in Philomath.

This experience was delightful, at first. Other children loved me, and so did my caregivers. I was kind of toilet trained. Because I got boring, this love and good care became less and less. One day, I fell out of my seat in the school bus and was hurt. The school blamed my parents. Of course, this was crazy. Mom and dad love me and take excellent care of me. They took me home where I had good caregivers, my family and therapists helping me learn to communicate better. I was not verbal.

I went back to school in 2005 with a better system. I now weigh 150 pounds, I cannot walk, and I may be sweet, but I'm hard to handle physically. My dad is ill and cannot help me very much. I'm ready to transition into adult care in a group home. The home and caregivers are sup-

posed to be loving, caring and competent. My mom is worried, but she cannot take care of me by herself. We'll see what this will bring.



Employment

By Susan Melero,
Corvallis

I work at Taylor Street Ovens, a bakery run by Cornerstone Associates. I sometimes take orders, stock silverware, and napkins. I stock cookies, but I don't eat them! I mostly work out front. I work three days a week.

I like the people and the food is great. I like the downtown atmosphere. I look forward to the fall when the college students come back.

Cornerstone Associates runs other businesses, including: Color Wheels, CornerStone Wood Products, Packing Plus, BJ BookBinding, Landscape Maintenance, Crystal Lake Janitorial, and Community Access.

2007 Calendar

SAAL Training

Pendleton, Sept. 11, 4 pm.
Contact Marcie Tafalla
503-725-8129.

Wallowa Lake

Campout: People First of E. Oregon

Contact Sandy Sheehy
541-962-8846.

SAAL Violence Awareness Training

Redmond, Sept. 15, 4-7pm.
Hosted by People First of Central Oregon.
Contact Marcie Tafalla
503-725-8129.

Buddy Walk: September 29, 2007

A fundraiser for people with Down Syndrome. Portland. Contact Whitnie Trost 503.612.0424
wtrout@nwdsa.org

SAAL My Voice, My Choice Training

Hosted by SPARC of Polk Community Living. Saturday, October 6. Monmouth Library 10-4. Contact Marcie Tafalla 503-725-8129.

