Sarah Goes To College
by Sarah Steele & Marilyn Hair

In 1939, James Stewart starred in a now-classic movie called *Mr. Smith Goes To Washington*. It's about a naïve and idealistic young politician named Jefferson Smith who is appointed to a brief interim term in the U.S. Senate. The politicians in the state he represents are self-serving and corrupt, and they think they can make Jeff Smith do their bidding. But Mr. Smith defends freedom, democracy and morality, and overcomes the corruption of Washington.

The story of *Mr. Smith Goes To Washington* inspires the title of this column. This is the year my daughter, Sarah Steele, evolves from receiving special services in public school to applying for the adult services that are provided to people with disabilities by state and federal entitlement programs.

Sarah is a senior in high school. She has goals and dreams for the future, and is beginning to make them happen. Sarah wants to go to college and live on campus. She intends to major in Spanish with the goal of becoming a Spanish/English interpreter. Like her senior-year classmates, Sarah will choose her college, apply for admission, and look for scholarships, grants, loans, and parents to pay for her higher education. As a person with FOP, she has another layer of needs: Wheelchair-accessible classrooms and housing, a mechanical lift for transfers, accessible bathroom and shower. Sarah will also need personal care attendants to assist with her personal needs and aides to help her in class and with homework.

Sarah has been working on college preparations since the spring of her junior year, when she took the Scholastic Aptitude Test, or SAT. During summer vacation she attended Do-It (Disabilities, Opportunities, Internet-working and Technology) and the Youth Leadership Forum, both week-long programs in our state of Washington to prepare high school students with disabilities for college. Along with our family, Sarah toured three college campuses and talked to the admissions counselors. She now has a first-choice college, and she has begun writing the application for admission and submitting transcripts and letters of recommendation for early action. The college will inform her of their decision by December 1st.

Completing public school and moving away to college is a pinnacle in life, for the students and their families, too. Making it happen when one has FOP is ever so much more complicated. Like Mr. Smith in Washington, Sarah will have some experiences that are disillusioning and some that are successful. Through this column in FOP Connection, we want to share with the FOP community how getting ready for college works out for Sarah.

If you have experience planning for or attending college, or other questions or comments, please e-mail us at sarahls@prodigy.net or marhair@prodigy.net, or write to us c/o the IFOPA address on this newsletter. We'll include your comments in the next column of Sarah Goes To College.

Her Special Education teacher said, "In all my years of teaching, Sarah is the first student I ever had who is going to college." Our family is excited and scared and a bit overwhelmed at the prospect of making it possible for Sarah to live and learn away from home.

"We deceive ourselves when we fancy that only weakness needs support. Strength needs it far more."

Madame Swetchine, 16th Century author

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**MARK YOUR CALENDAR**

November 16
Spaghetti Dinner with Murder/Mystery play in Eastford, CT in honor of Jasmin Floyd

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Sarah Goes To College
by Sarah Steele & Marilyn Hair

Sarah's sister, Mollie, was given a Tantrix puzzle for Christmas. It consists of 10 8-sided tiles, numbered 1 through 10. Each number is red, yellow or blue. When you turn a tile over, it has 3 lines: a red, a yellow, and a blue line. Some of the lines are straight and some are curved. The object of the game is to arrange the tiles to make the lines form a loop or circle.

There are ten different loops to solve. You start with tiles 1, 2 and 3. The number on tile 3 is yellow, so make a yellow loop. Easy, huh? Now break up the loop, add tile 4, and make a red loop. The more tiles you use, the harder it is to make a loop. When you use all 10 of the tiles, there is a solution for each color.

For an adult with a disability, arranging the supports needed to live independently is like solving a Tantrix puzzle. The goal is to make all the pieces of your support network form a loop or circle that provides everything you need. The circle is not one-size-fits-all. One person might need 3 pieces to form a complete circle of support; someone else has greater needs and requires more pieces to form a complete circle. If it sounds complicated, it is.

In the November issue of FOP Connection, we reported that Sarah has participated in college-preparation activities in high school, taken the Scholastic Aptitude Test, and submitted her application to college. Now, our family has begun working with some of the pieces that will form the circle of support for Sarah to attend college and live away from home:

1) In December, Sarah announced on FOPONLINE that she has been accepted to attend her first-choice college, Seattle Pacific University in Seattle, Washington. Her Dad, Richard Steele, is a Professor of Theology at Seattle Pacific. SPU has a new dormitory with some accessible ADA rooms. It is 11 miles from home. Now that Sarah has been accepted, she can begin talking to the Disabled Student Services Office about accommodations. Every college in the U.S. that receives federal money has a DSS office. Sarah applied under the early action timeline so she would have plenty of time to arrange her accommodations.

2) We consulted a lawyer. Our wills were written when the children were small and we lived in a different state. When Sarah turned 18, she outgrew the guardianship arrangements for minor children in our wills. Our lawyer helped Rick and I draw up new wills which include a special needs trust to provide for Sarah if we both die.

Sarah also signed a durable power of attorney which empowers her Dad or me to be her "attorney-in-fact". This lets us continue to be Sarah's advocates by talking to her doctors and having access to her medical records. We can also sign legal documents for her. Under the power of attorney, Sarah can speak and sign documents for herself and her parents can't overrule her decisions. She can revoke the power of attorney any time, or fire us as her attorneys-in-fact. Sarah and her Dad and I also signed a rent agreement which says she will pay $400 a month to live in our home. This will help her qualify for the maximum amount of monthly SSI payments.

Our lawyer gave us the name of another lawyer who specializes in disability law. In one appointment with him, I gathered a lot of valuable information about services available to people with physical disabilities in our state. He reviewed the draft of our wills and special needs trust and suggested a few revisions which our lawyer included in our wills.

3) Sarah applied to the Social Security Administration for SSI, or Supplemental Security Income. This monthly stipend is available to adults age 18 and above who are disabled and have less than $2000 in assets. SSI is also available to children when their parents have limited assets. We completed the 10 page application and Sarah signed releases to let Social Security contact her doctors and see medical records that document her disability. We opened a checking account in Sarah's name and arranged for direct deposit of her SSI check. Both parents' names are on the account. If her application is approved, she will begin receiving a monthly check on February 1st, one calendar month after she turned 18. SSI pays $552 each month for rent, food, clothing and incidentals.

When a person receives SSI, he also qualifies for Medicaid health insurance. Since Sarah is covered under our family's health insurance policy, Medicaid will pay the co-payment for her doctors appointments and prescriptions, and for medical care and equipment that's covered by Medicaid but not by our family health insurance policy. When she is too old to be covered as a child under our family policy, Medicaid will be her primary insurance.
Another piece in Sarah's circle of support is college financial aid. On January 1st, along with every other parent of a high-school senior who plans to go to college, we filed a FAFSA, or Free Application for Federal Student Aid. The FAFSA is an abbreviated tax return; parents and students report information about their finances for the year just ended. One month after you file the FAFSA, you get an SAR, or Student Aid Report, which will give your EFC, or Expected Family Contribution. Colleges use this standardized information to prepare a financial aid package for each student. Colleges offer a combination of grants, scholarships, loans and work-study dollars to pay the difference between your EFC and the cost of attending their college.

Sarah also assembled a Senior Portfolio for the Career Center at her school. Seniors who submit a portfolio of their interests, accomplishments, and plans for higher education are considered for scholarships that are awarded to graduating seniors at Lake Washington High School.

In the fall of senior year, Sarah applied to the Department of Vocational Rehabilitation for help with postsecondary career training and employment. DVR is a federal program that is administered by each state. Sarah qualified for services right away because she has needs in several areas, including mobility and personal care. She was assigned a DVR counselor who will work with her and the college. Sarah can be a client of the DVR until she finds employment in her chosen field. DVR requires parents to disclose financial information and contribute towards the things DVR provides, if they have resources, as long as they claim their child as a dependent on their federal tax return. The Dept of Vocational Rehabilitation pays for items such as tuition, books, computers, classroom aides (but not personal care attendants), transportation, wheelchairs, and hearing aids.

Sarah, her Dad and I went to campus to meet with the Program Coordinator for Disabled Student Services at Seattle Pacific University. The Program Coordinator asked about Sarah's living needs and what accommodations and assistance she will need to live in the dorm. Sarah was also asked what educational accommodations she has used in public school, and the Program Coordinator told us the college will provide note-takers, textbooks on CD where available, accommodations for taking tests, and accessible technology such as screen reader, speech recognition, onscreen keyboard and word prediction. Students must provide their own personal care attendants. A double room with a private bathroom in the new dormitory would accommodate Sarah if the bathtub is remodeled into a roll-in shower. Sarah signed a release to give the DSS Program Coordinator permission to talk to her parents, college professors and other staff, and her DVR counselor. Sarah was asked to bring a letter from a doctor to document her disability and describe how it affects her in an academic setting.

Sarah's last IEP meeting was held at high school. States use their own terms for special education services; in Washington State, students in special education have an Individual Educational Plan, or IEP. Beginning when the student is age 14, all schools must address their "transition" to life after public school. Sarah's DVR counselor attended her IEP meeting, along with her Special Education teacher, Occupational Therapist, the school nurse, an aide, 3 classroom teachers, school psychologist, parents, and, of course, Sarah. The special ed teacher and related services staff enumerated and recorded all the accommodations Sarah receives. The teachers reported on Sarah's progress in their classes. The DVR counselor was taken to see the school's accessible bathroom and Barrier-Free power lift which Sarah uses to transfer. The group discussed computer technology that might be useful for college work, an emergency plan in case of wheelchair breakdown, providing a cell phone and a way for Sarah to handle it without assistance, and attendant care. Sarah's DVR counselor described the services her agency provides, and said that it will be difficult to find funding for enough hours of attendant care to complete her circle of care.

The next step in helping Sarah prepare for college is to order an Independent Living Evaluation. An agency will be hired to document which activities of daily living Sarah can do for herself and which she can do with assistance. Right now DVR and SPU each think the other should pay for this evaluation. We hope their disagreement won't delay Sarah's preparation for college. The subsequent step will be to find funding for attendant care. The lawyer who specializes in disability law gave us the name of someone to call at DSHS, the state Department of Social and Health Services. There is also some attendant care available to people who qualify for Medicaid. We know where to start when it's time to pick up that piece of the puzzle.

The more tiles there are in the Tantrix puzzle, the harder it is to connect them in a circle. Sarah's circle of support has eight pieces so far. We know it will be complicated for her to go to college. We're hoping, praying, and working toward solving the puzzle in time for the start of classes next September.

February 2003
Sarah钢 goes to college

Much Paper Work, Many Hands Help Put Puzzle Pieces Together

By Marilyn Hair and Sarah Steele

Sarah Steele, scholar and newly graduated, is ready for college. Congratulations, Sarah, and keep us posted.

Developing supports to enable a person with a severe disability to live independently is like putting together the pieces of a puzzle. In September, 18-year-old Sarah Steele plans to move into a college dormitory and begin studies to earn a Bachelor's degree in Spanish. We are working with nearly a dozen puzzle pieces to arrange the supports she will need. In a letter of medical necessity requested by Medicaid to pay for wheelchair repairs, Sarah's pediatrician wrote, "It will require extraordinary will and perseverance on Sarah's part to accomplish this transition in life." This is where Sarah's perseverance has taken her since the last "Sarah Goes to College" column:

1. Sarah has been awarded a Provost Scholar's Award for $5000 to attend Seattle Pacific University. It is renewable for 4 years.

2. Sarah's Dad and I set up a trust fund when she was a baby, and our lawyer recommended that we begin to spend it when Sarah turned 18. We are using it to pay for such expense as Sarah's school supplies; out-of-pocket medical, high school graduation and college preparation expenses.

3. Last December, Sarah signed a Durable Power of Attorney that gives permission to her parents to speak on her behalf and talk to doctors and public agencies who work with her.

No one has asked to see the Power of Attorney, although I have been asked if Sarah has signed this document. Medical and entitlement providers and college staff address their questions to Sarah, and I am getting used to my new role of listener.

4. Sarah applied for Social Security in December. She now receives a Supplemental Security Income (SSI) check for $525 by direct-deposit on the first of each month. She also became eligible for Medicaid health insurance.

5. Sarah and I met with her counselor from the Dept. of Vocational Rehabilitation to write a blueprint for her career and educational goals, including the costs. Because we claim Sarah as a dependent on our federal tax return, her Dad and I submitted a financial disclosure of our assets, income and expenses to DVR.

6. DVR contracted with an Assistive Technology Specialist to do an Independent Living Evaluation in the dorm where Sarah will live. In March, Sarah and her Dad and I, the DVR Counselor, the University's Disabled Student Services (DSS) Coordinator and Buildings and Grounds Supervisor, and the AT Specialist gathered at Emerson Dormitory. The Specialist asked Sarah how she goes about her life: "How do you transfer? Use the toilet? Shower? What kind of bed do you sleep in?" Sarah demonstrated the features of her Permobil wheelchair. She also described her computer accessories: the MicroTrak mouse, dowels for typing, ScreenDoors onscreen keyboard and word prediction software, StickyKeys to type capital letters, and a Palm Pilot. The AT Tech offered suggestions that will help her do college-level work:

A. A new computer with the Windows XP Operating System.

B. Miniature keyboard, to accommodate her limited range of motion.

C. IPAC Pocket PC that uses Microsoft Office software, such as Word and Outlook, and can download files to the desktop computer.

D. Kursweil 3000 editing software to scan textbook pages, read text aloud, and take notes on the computer. SPU uses this program in the DSS office.

E. Scanner and printer.

F. An environmental control unit to access phone, lights, computer, thermostat, TV, and VCR that can be activated by a switch or voice.

The group toured a double room with private bath and shower.
Sarah would live there without a roommate; her attendant would sleep in the second bed. The adjustable-height desk is tall enough for Sarah's knees to fit underneath as she sits in her wheelchair. The University will provide a sensor to Sarah's wheelchair that will remotely open her room door when she drives past the electric eye mounted on the wall. The room's only drawback is a step into the shower. In a follow-up visit Sarah took her shower chair and a vendor brought a DMA-brand power floor lift. A practice session in the dorm room demonstrated that the bathroom is suitable but the shower will need to be remodeled into a roll-in, universal access shower. The University approved this remodel before the AT Specialist even submitted his report!

The AT Specialist will recommend the accommodations Sarah will need. DVR and her parents will negotiate who will pay for it. The AT Specialist will continue to be part of the team until Sarah's accommodations are ready, including details like setting up her computer system in the dorm room.

7. Sarah got a flip-style cell phone to wear on a necklace so she can call for assistance anytime.

8. An adult friend volunteered to be Sarah's attendant for half a day each week, and one of Sarah's high school aides is interested in working for her part-time. The respite worker who has helped Sarah for several years told us she wouldn't continue.

I contacted the state Dept. of Social and Health Services to apply for attendant care, specifically the Community Options Program Entry System (COPES) Program. This is Washington state's name for a Medicaid program that pays for personal care and housekeeping so that people who need assistance can live in their homes.

Within two weeks, DSHS sent a nurse to our home to do an intake evaluation. Based on Sarah's limited income and level of need, she was given the maximum number of attendant care hours, 147, each month. The attendant care hours were offered immediately. A home health care agency arranged for two caregivers to cover three evenings, plus two overnights. The caregiver helps Sarah take her shower and get ready for bed. She changes her bed sheets, washes her laundry and tidies her room. The overnight caregiver gets Sarah up and dressed for school two mornings each week. IFOPA President Jeannie Peeper observes that it will be easier for Sarah to get used to hired caregivers now, before she faces the additional change of moving and starting classes.

When Sarah moves to college, we will ask COPES to fund and staff personal and overnight care, and DVR to fund aide-time for Sarah during class and study time.

9. At the High School Senior Outstanding Academic Achievement Program, Sarah was awarded the U.S. President's Outstanding Academic Excellence Award for earning a 3.5 or above grade point average throughout high school. She received the Washington State Principals' Scholars Top 5% of Senior Class Award, based on leadership, community service and grades. Sarah was chosen by the local newspaper, the King County Journal, as the Top High School Graduate in the Most Inspiring category. Her picture was in the paper, and the newspaper ran a story about her.

10. Sarah attended her Prom. 11. Finally, she went to Premiere, SPU's freshman orientation. She met future classmates and professors, registered for fall classes and got her first quarter schedule, which includes an 8 a.m. class! She asked the DSS office for accommodations to take the math qualifying test, and rather than taking it with other incoming freshmen during Premiere, she will take it during summer vacation in the DSS office.

To keep her study skills sharp, Sarah will take one-day computer courses in Word, Excel, Power Point and Outlook at the Community College this summer.

The pieces in Sarah's support system are beginning to fit together. Many people are working to help her make the transition to college, and a crowd of onlookers is cheering her on.

OVERCOMING OBSTACLES

"Here is a picture of my hairbrush. It's made very easily with a piece of conduit pipe and a vent brush. You grind down the brush to fit into the pipe and secure it with a small screw. The whole thing is about 2.5 feet long. It could be longer, as needed."

Submitted by Pamela Fike
The countdown is on for fall quarter to begin. By the time you read this, Sarah Steele will be living at college. Classes at Seattle Pacific University begin September 29th. This column continues the story of Sarah's transition to higher education and adult life.

In June, Sarah's Department of Vocational Rehabilitation (DVR) counselor asked Sarah and me to attend a meeting to review the Individual Plan for Employment (IPE) the counselor has written for Sarah. The idea is to list everything Sarah will need to gain in order for her to work in her chosen field, and the cost. One of my topics for the meeting was to negotiate which of Sarah's needs her family would pay for, and what DVR would provide. The first thing the counselor asked was whether Sarah receives Supplemental Security Income. Sarah began receiving SSI in February. The counselor took the financial disclosure forms I had completed and set them aside. Since Sarah has met the financial and disability qualifications for SSI, DVR will provide the services she needs for college. This was wonderful news! But I learned that if Sarah had qualified for SSI before she applied for DVR services, the issue of parents' income and assets would never have come up. So, if you apply for services from the DVR, apply for SSI first!

Sarah's counselor asked permission to invite the DVR medical consultant to join the meeting. We agreed since it's in Sarah's interest for DVR to understand her medical condition. The medical consultant told us that Sarah is an unusual client for DVR. Everyone who has FOP gets used to being unusual, but the consultant emphasized that most DVR clients do not have such extensive needs for assistance. Sarah will require more services and be more expensive than the average client. The medical consultant also told Sarah that having attendants work for her will be part of her life, and one of the life skills she will need to develop is working effectively with the people who help her. He reminded her that the success of her plan to move to college depends on her health. "If you get sick," he said, "your whole plan will fall apart."

Sarah's counselor showed us the IPE document. It included a computer with hardware and software for accessibility, tuition for computer classes at the community college, 43 hours per week of attendant care during four years of college, tuition up to the amount it would cost to attend a public university, books and fees, new hearing aids, DMA floor lift, and shower chair. The medical consultant asked me to pursue funding for the floor lift and shower chair through our family health insurance policy and Medicaid. After Sarah's rehabilitation doctor prescribed the floor lift, our health insurance company assigned a case manager for Sarah.

DVR denied our request to replace the 9-year-old lift in our 1994 Ford van because Sarah doesn't own the van. So we bought a Braun Millennium wheelchair lift and EZ-Lock tie down system. This will be Sarah's transportation during her college years. The equipment can be claimed as a medical deduction on our tax return.

Sarah's new computer system was set up at our home in August, and Sarah will learn to use it before classes start. The computer will be moved to college when the dorms open for Orientation on September 25th.

Now we turn our attention to attendant care. In the spring, Sarah applied to the Department of Social and Health Services and was approved for the Community Options Program Entry System (COPES). The purpose of the COPES program is to assist people who need attendant care to live outside a nursing home setting.

A nurse conducted Sarah's intake evaluation and wrote a care plan. After a few weeks, a case manager from the local Independent Living Center was assigned. Once again, Sarah's desire to live independently combined with her need for assistance in all activities of daily living makes her case exceptional for the Dept. of Social and
Health Services. Sarah's new case manager said she has never worked with anyone with severe needs who wanted to move out on her own. On the other hand, Sarah's case manager knows about FOP because she has another client who has FOP, Elizabeth Bay.

A re-evaluation must be conducted within a month after a client is assigned to a case manager. This meeting was held in our home. The case manager, her supervisor, Sarah's DVR counselor, one of Sarah's DSHS attendants, Sarah, and Sarah's parents attended. The agencies that help people with disabilities do not tend to communicate with each other or coordinate their efforts, so it was a momentous occasion when Sarah's DSHS and DVR staff sat together in our living room. It is also unusual for a DSHS supervisor to attend a re-evaluation meeting. Having extensive needs makes it harder to achieve independence, but it has the advantage of getting the attention of providers and being able to qualify for services right away.

There are rules about what kinds of assistance the attendants hired by DVR can provide. Attendants who work during school hours can go to class and help the client with homework. They cannot get the client up or dressed, take the client to the bathroom, help with meals, or give medication. There are also rules about what attendants hired by DSHS can provide; these attendants do personal care, meals, light housework, the things DVR attendants can't do. The first thing the DSHS supervisor said was that these rigid rules would make it difficult for Sarah's needs to be met. Sarah must have someone with her all the time, and it would be impractical for an attendant from DSHS to replace the attendant from DVR for an hour to assist Sarah with lunch and toileting. The DSHS supervisor asked Sarah's DVR counselor for some flexibility, and the counselor agreed that the attendant who helps with schoolwork could also help Sarah with personal care during the day.

The DSHS case-manager reviewed Sarah's medications and doses. She said attendants are not allowed to dispense medications. They can hand pills to a client in a medicine cup, but they can't touch the medicine. However, there is a program run by the Aging and Adult Services Administration in Washington State called Self-Directed Care. If a physician writes a prescription that says a client of DSHS is capable of directing an attendant, the attendant is authorized to open prescription bottles and give medications. Sarah has over-the-counter vitamins, which must be crushed because her jaw is locked, and capsules whose contents must be poured out and stirred into applesauce or pudding. Under the Self-Directed Care program, Sarah's attendant will be able to give her these medications.

For three years, Sarah has been involved in a program at the University of Washington called DO-IT (Disabilities, Opportunities, Internetworking and Technology). DO-IT is held on the UW campus for 12 days in August. DVR said that attending this program will help Sarah prepare for a career, and she was given 10 hours a day for a total of 120 hours of attendant care. DSHS gave 12 hours a day for the length of the DO-IT program, and with some juggling so attendants could cover the other 2 hours, Sarah had around-the-clock care.

Living in the dorm at the University of Washington and attending the DO-IT program turned out to be useful practice for college. Sarah gained a sense of independence as she shopped for supplies, stayed up late, and was responsible for her own routines. She learned to use her new DMA floor lift, which was kindly supplied by Sarah's long-time vendor before the funding was approved. We made a spreadsheet with the doses and times of medications and printed a checklist to post on the wall so Sarah could keep track of what needed to be done:
- Take meds
- Turn on/off cell phone
- Set alarm clock
- Charge wheelchair
- Charge cell phone
- Set wristwatch alarm (for afternoon meds)

We also developed a page of emergency medical information. Sarah gave a copy to the DO-IT staff and kept one with her. It includes a description of FOP, emergency contacts, Sarah's doctors and contact information, and her medications and dosages. On the back is an article "Obtaining Tissue Samples During Emergencies" by John Cali and Drs. Kaplan, Shore and Zasloff that explains how to send tissue samples to the FOP lab. The page is based on a brochure created by Nancy Sando, who has FOP.

It was helpful to schedule the attendants for long shifts to minimize the number of times the next attendant might not arrive. Sarah worked out how much time she needed to get ready in the mornings, and discovered that if she ate yogurt in her room instead of going to the cafeteria, she could sleep half an hour longer. She learned to use her cell phone and keep track of her room key and meal card. She even implemented her back-up attendant system (me) when her attendant had an emergency.

DVR and DSHS have agreed on Sarah's attendant schedule when college begins. Between the two agencies, Sarah will have 24-hour attendant care from Monday morning until Friday afternoon. She will come home on the weekends and family members will assist her. If Sarah has an activity or homework at college during the weekend, she will hire an attendant or a family member will come.

The University has agreed to build a roll-in shower for Sarah. The Buildings and Grounds Supervisor asked her to come to campus for a final "fitting" before they began construction.

Sarah at School cont. on page 16
Sarah is assigned to a first floor room with private bath that could house four students. There will be a bed for Sarah’s attendant. The bathroom wall will be moved to make the bathroom 12 inches wider, and a wall-mounted sink will be installed outside the bathroom. An electric eye will be added so Sarah can open the door.

We learned that what our lawyer said is true: “Don’t give Sarah money”. When a person receives SSI, cash gifts must be reported, and after receiving $20 in a month, cash gifts are subtracted dollar for dollar from the next SSI check. Gift certificates don’t count as cash gifts. Also, Sarah can earn up to $65 in a month without being penalized; if she earns more than $65, her SSI check is reduced by 50¢ for every $1 earned.

Sarah’s support network is coming together. Sarah had a taste of college during the DO-IT program, and she can’t wait to move to the dorm. The college staff is eager for Sarah to matriculate. Supporters in the IFOPA are cheering her on. We’ll tell you about Sarah’s life at college in the next installment.
Sarah speaks:

The day before I moved to college, my mom asked if I was nervous. "No," I told her, "I'm excited. Some people say that college was the best years of their life." In late September, I moved to Seattle Pacific University (SPU), a 3000-student Christian college in downtown Seattle, Washington.

I am taking 12 credits in fall quarter. Spanish and Freshman Seminar are each five credits. Intermediate Spanish is a lot of review since I took Spanish for five years in public school. Freshman Seminar requires writing a short paper every week. Learning to write at a college level is a challenge! These classes meet one after another from 8 am to 10:50 am Monday, Wednesday, and Friday. Freshman Seminar was scheduled to meet in a building that has stairs at the entrance and is far away from where my Spanish class meets, so the Disabled Student Services (DSS) office moved my Freshman Seminar to a room down the hall from my Spanish classroom.

My third class is Women's Choir. It is a two-credit class, which meets Tuesday and Thursday in the afternoon. Fall quarter has gone well and I plan to take 15 credits during the winter quarter.

I live in a five-story dormitory called Emerson Hall. The dorm is three years old and has many nice features like a laundry room, gym, elevator, underground parking, suites with bathrooms, and a kitchen and lounge on each floor. There are four floors for women students and one for men.

The Residence Life program organizes social opportunities for students who live on campus. Each dormitory floor has a Peer Advisor and a Student Ministries Coordinator. My floor-mates eat dinner together in the dining hall every Thursday. We have a floor discussion group that meets once a week, where we share our life stories.

The university has done a lot to make living on campus possible for me. They remodeled my dorm room, which has a roll-in shower and a drive-in closet. There is space for my wheelchair and equipment, and two single beds for my attendant and me. My room is on the first floor for easy access and emergency exit. It has a height-adjustable desk, and I drive my wheelchair underneath it to work at my computer. The Department of Vocational Rehabilitation (DVR) purchased my computer, a Gateway with a CD/DVD drive, plus computer adaptations that help me study. These adaptations include a cordless mini-keyboard, mini-trackball mouse, and Kurzweil 3000, which is reading, writing, and learning software that lets me read textbook pages on the monitor, highlight text, and extract notes. The computer can read the text to me with Kurzweil, even in Spanish. I also have a combination scanner/printer and handheld iPAC computer that downloads to the desktop.

I open my room door by swiping my ID card across the keyless entry pad. The barcode unlocks the door and it swings open. There's a switch on the wall, which I push with my wheelchair to open the door from inside the room. My attendants each have an ID card they use to unlock the outside door of the dorm and my room door when they come to work. There is an underground parking place reserved for my attendant.

I have an attendant with me all the time. My daytime attendant, Linda, is paid by DVR. She works 43 hours per week. Two attendants, Nabila and Kelly, work alternate nights Monday through Thursday; they are paid by the Community Options Program Entry System (COPES), a state program that provides personal care. I have one volunteer attendant who comes on Tuesday mornings.
I met Linda the day before classes started. The first week I felt uncomfortable with her because she laughed all the time and I felt like she was laughing at me. Maybe she was nervous. Finally we had a private talk and she told me not to worry about hurting her feelings, but to let her know what I wanted and what bothered me. She wanted us to have a good working relationship. Once I was honest, I have gotten used to working with Linda and our relationship has improved.

My overnight attendant Nabila works for a home health care agency and has been taking care of me since last spring. Kelly was one of my aides in high school. She is an Independent Provider and I am her only client. Kelly has a different job during the day and the hours she works for me depend on her work schedule at her day job. Once a week, she has to leave at 6:30 am, so I have to get up at 5:30 am and be dressed at 6:30 am when Linda arrives. I have to remember to go to bed early the night before or I fall asleep in class! Some evenings, Kelly comes at 7:30 pm, two hours after Linda leaves. My dad is a professor at SPU, and he stays with me until Kelly arrives. We eat dinner together.

I am happy to say there has not been a single time when my attendant has not shown up for work. A few times, an attendant has told me ahead of time that she can’t come, and I have been able to rearrange the accommodations and procedures for students who have disabilities at SPU buildings. The Mailing Services Department collects the mail from my student mailbox and I pick it up at the desk. When I couldn’t find food I could eat for lunch, I met with the food service director. I suggested some soft, protein-rich foods I enjoy, and they added tuna fish and egg salad to the lunch buffet. Also, I can register early for classes each quarter. This gives the DSS office time to scan my books and change room assignments, as it did fall quarter. Early registration allows me to get into the classes I want before they are filled.

There were bound to be some unexpected challenges in my move to college. The first week, I wrote a paper on my iPac handheld computer, and when I tried to download it onto my computer, the computer didn’t recognize it, so I couldn’t print it. I called DVR for technical support, but the paper had to be retyped so I could turn it in on time. Thanks, Dad!

Another challenge is getting enough sleep. I enjoy watching TV with my floor-mates until 11 pm, and I go to bed at midnight. The problem is that I have an 8 am class, and I was falling asleep in class. I’ve been taking a nap on weekend afternoons and going to bed earlier on the night before my 8 am class.

Once, my wheelchair broke down. I used my uncomfortable old manual chair while my mom took my Permobil power wheelchair in for repair. It took 10 days, three service calls, and an overnight delivery of parts, not to mention patience and perseverance from everyone, before the wheelchair was fixed. I was able to stay at college and didn’t even miss any classes.

I love college. I’m learning and making friends. I’m also gaining important life skills like working with attendants, supervising my personal care, keeping track of my belongings, and managing my schedule. Living away from home is great. I’m having the time of my life.

Marilyn speaks:

“We are at the edge of the waterfall, about to go over. Last night, Sarah’s dad dreamt about falling over the brink. I dreamt that Sarah was attacked and nobody advocated for her when I wasn’t there. This was my journal entry the morning my daughter, Sarah, attended her first college class at Seattle Pacific University.

The day Sarah moved into the dorm, I accompanied her to the US Bank to buy quarters to use in the washing machine. I was transported back to last February when Sarah opened her checking account. We chose US Bank because it had this branch location on the campus. The efforts of eight months ago made this transaction easy. Opening her bank account was one of dozens of preparations Sarah made to get ready for college.

Sarah spent the nights at home that weekend. She returned to campus Sunday evening to attend her residence hall meeting, and stayed overnight with her long-time respite worker, Somer. The next morning, Somer wrote this e-mail: "I just got home from staying with Sarah, and we had a really good night. I think she was nervous because she was up at 3 am, and again at 4 am and 5 am. All the meetings went well. Sarah was quite the social butterfly going around introducing herself to people and talking it up with everyone. I stayed in the background and let her do her thing. We didn’t get into bed until almost midnight. It was hard this morning..."
leaving her as she went off. I almost started crying because I am so proud of her. I still don't believe she is old enough to be in college. You and Rick should be so proud.*

Sarah's dad, Rick Steele, is a professor in the School of Theology at Seattle Pacific University. When he introduced himself to his students on the first day of class, Rick told them he is the parent of a freshman. A student raised her hand and asked, "Are you Sarah Steele's father? Sarah is on my floor. At the meeting last night, she volunteered you to be in the Emerson Hall Film Festival!" When Rick related this exchange, he added dryly, "Imagine my joy." But, he was smiling.

Sarah called me after the first day of classes. As I hung up, I said, "Talk to you soon." Sarah responded, "Well....maybe."

Making it possible for Sarah to move to college is the most gratifying thing I have ever done for her. Seeing her custom-remodeled dorm room, watching university staff welcome her, working with a team of providers (Social Security, Medicaid, Independent Living Center, and Department of Vocational Rehabilitation) is immensely fulfilling. But, it is a huge transition. Our parental roles have shifted. Rick is more involved in Sarah's daily routine. He drives the wheelchair van so he is available if Sarah needs transportation, and he stays on campus until Sarah's overnight attendant arrives. Sarah calls Rick when she needs help with her computer or wheelchair, or has questions about university procedures. Our schedule at home is different, too. Weekdays are quieter and evenings are more leisurely, but the weekends are busier than ever. Sarah is tired when she comes home on Friday nights. She brings dirty laundry, a grocery list, and homework. I spend the weekend helping her get ready for the next week.

As Sarah said, there have been some challenges. I notified Social Security when Sarah moved to campus and SSI did a re-evaluation of Sarah's eligibility. SSI ruled that room and board costs more than a person who depends solely on SSI income can afford. Paradoxically, Sarah's monthly SSI check has been reduced by $200. This is a penalty she will have to pay in order to live in the dorm.

Another challenge was the venue of the fall choir concert in the sanctuary of the campus church, Seattle First Free Methodist. The chancel has three short steps, an insurmountable obstacle for Sarah's power wheelchair. A university staff member built a ramp, and, on the night of the concert, I went with Sarah to try it out. It is a bulky contraption made from rough 2x4s, in sharp contrast to the polished oak woodwork in the sanctuary. I suggested that someone stand beside Sarah, to make sure the wheelchair didn't fall off the planks. After Sarah tested it, the ramp was dismantled and stored under the front pew until it was Sarah's choir's turn to perform.

During the concert, the men's choir filed in procession down the center aisle and up the three steps to the chancel. After their performance, the singers recessed, except for four tenors in tuxedos. The young men assembled the ramp and stood beside it while Sarah drove down the center aisle, up the ramp, and onto the chancel. I could scarcely keep myself from applauding. It was a metaphor for the graceful approach the University has taken to meeting Sarah's needs.

There is postscript to this story: The sanctuary was remodeled last summer, and the architect was in the audience at the concert. He volunteered to design a permanent ramp. The next concert was a Music Department Christmas extravaganza held at Benaroya Hall, home of the Seattle Symphony. Sarah sang Mendelssohn and Gounod with 200 fellow students. To see her on the stage of one of the finest concert halls in the world, before an audience of thousands, was stunning. We couldn't have imagined this kind of achievement 18 years ago, when Sarah was diagnosed with FOP.

Is all this effort worth it? Not everyone would say it is. I talked to my doctor about our work to help Sarah live at college. He responded, "Wouldn't it be easier just to let Sarah live at home?" After the University DSS Coordinator took an inventory of Sarah's needs, she said, "Do you think Sarah could commute?"

Making it possible for Sarah to go to college and live on campus takes tremendous effort from a host of people, including Sarah. We think it is worth it. Sarah is gaining freedom, independence, and higher education. Being able to attend college will raise her expectations of what she can do in life. As her dad said, "This is the best thing that ever happened to Sarah, and she knows it!" *

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**An article was recently published in The Journal of Bone and Joint Surgery entitled "In Vivo Somatic Cell Gene Transfer of an Engineered Noggin Mutein Prevents BMP-4-Induced Heterotopic Ossification" by Dr. Frederick Kaplan, Dr. David Glaser, Dr. Eileen Shore and other colleagues. The article can be obtained through the IFOPA's research center in the IFOPA office, or go to www.ifopa.org, click on resource center, and contact us by email to obtain a copy of the article.**