

On Your Own: Transitioning Teens

By Emily Pulley

Once a week, Keegan McFalls walks to the student health building at Brigham Young University (BYU) to give himself a subcutaneous infusion of immune globulin (SCIG). The immune globulin keeps his

immune system working, allowing his body to fight off infections. Keegan, 18, has Common Variable Immune Disease (CVID), and he doesn't think it's any big deal. During the two-hour infusion he watches a movie, plays pool or attends a class seminar—all without attracting attention.

Keegan and his brother, Konner, 20, were both diagnosed with CVID as children, and their conditions haven't dampened their ambitions: Keegan hopes to attend law school after BYU, while Konner, a student at Evergreen State University in Olympia, Wash., wants to be a college photography professor.

Though their ambitions are well defined, Keegan and Konner have already achieved a lot. Not only have they made the transition from their family home into college life, they've done so while meeting the challenges of managing the disease they have in common.

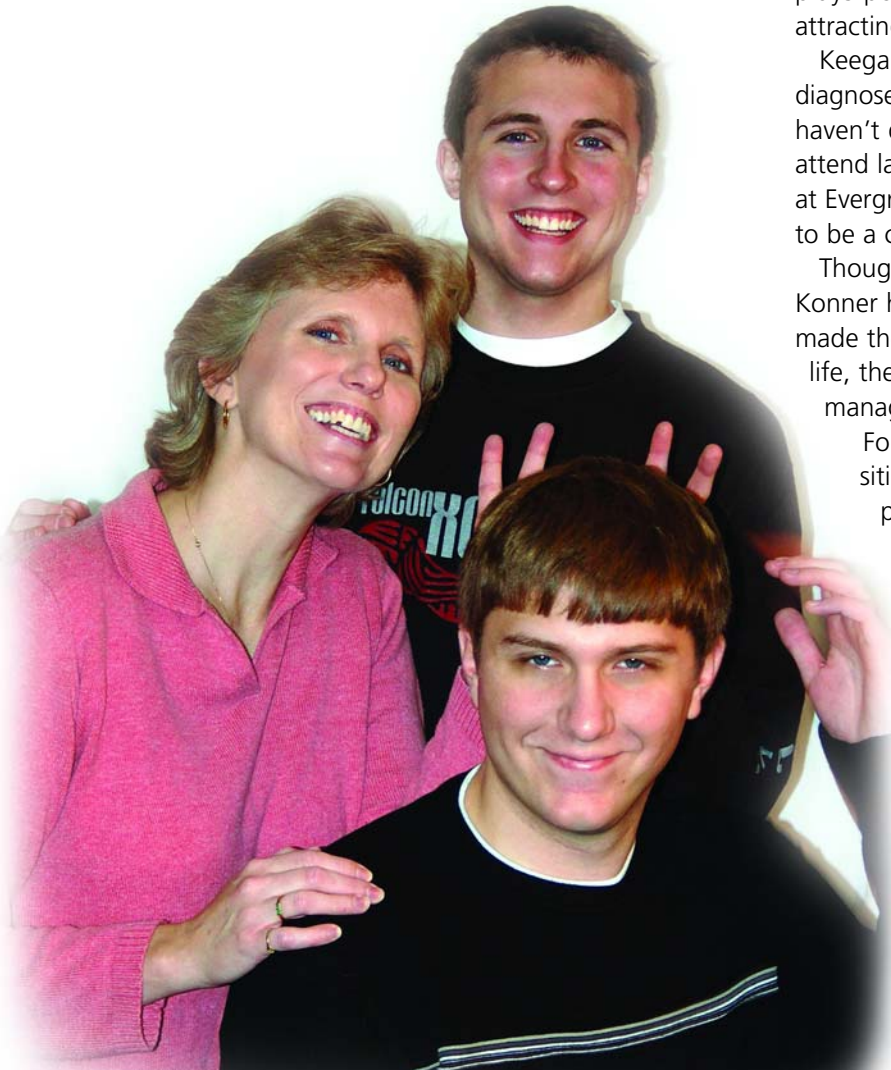
For a young person with a chronic condition, transitioning to adulthood takes years of planning and practice. The McFalls family offers this advice:

Children first must understand their disease state.

At age 13, Konner was fed up with his infusions and asked his mom, Kris McFalls, if he could stop taking them. When summer break came, she let him stop, with the support of his physician. After a couple of months, he wasn't feeling well and resumed his infusions. Kris says she allowed him to stop because she wanted Konner to understand the importance of the infusions and let it be his choice to take them.

Today, Konner uses a port for his infusions and is assisted by his mom, who visits his dorm room and helps him connect the IV.

Kris, Keegan (standing) and Konner McFalls



“My transition has been easy,” said Konner. “I knew anywhere I went I was going to be able to get my medicine. It was not too much of a change from my life as it was.”

Kris has many tips for families with transitioning teens. Parents and physicians should share information to help educate young patients. Young people should be encouraged to ask questions during doctor visits. If routine treatments are needed, children should be taught to help themselves or they should know enough to be able to instruct someone to help them.

In fact, Keegan now gives himself infusions and handles his healthcare needs on his own. “My transition was not too difficult,” said Keegan. “The only part I was worried about was whether or not I would do the SubQ [subcutaneous] infusion the right way. After doing the infusion a few times, I got used to it. From there it was easy. The only thing difficult to cope with was figuring out the best way to explain to people why tubes were coming out of my stomach.”

Other issues transitioning teens must consider include getting their own health insurance, knowing the names of their medications and how they are administered, understanding any allergies they have, recognizing the signs of possible side effects of the medications, making their own medical appointments, and learning to eat a healthy diet and exercise regularly.

Kris says her sons always have been independent, making the transition to college a smooth one for both young men. To facilitate his transition, Keegan switched from using a port to the more portable SCIG infusion method, so his weekly infusions take little effort and allow him to stay active during the treatments. Konner is planning to switch to subcutaneous infusions, which will allow him even greater independence.

Planning is the most critical transition tool, according to Kris, who raised her

kids as a single mom. She remembers that Keegan seemed to be constantly ill as a baby. After repeated trips to the doctor, Keegan was finally diagnosed with CVID at age 3. Because this diagnosis came the week of a big camping trip, Kris says her first response to the doctor was, →

Teens and Parents: Start Your Transition Today!

Here is a helpful list to get you started with your transition plan. Respond to each point with **Yes**, **Sometimes** or **No**—and have your parents do the same. Then, compare answers. For every **Sometimes** or **No**, set a date to turn the **Sometimes** or **No** into a **Yes!** For more in-depth worksheets go to www.cms-kids.com/CMSNTransition.htm.

	YES	SOMETIMES	NO
1. I know my diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I can explain my symptoms to medical professionals without help.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I carry an insurance card.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I carry emergency medical information.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I know what medications I take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I know the doses of my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I know what the medications are for.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I know the possible side effects of my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know what to do if I experience a bad reaction from medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I know what my allergies are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I have an EpiPen and know how to use it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I call for prescription refills myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I can tell a medical professional about my health history.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I have made my own appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. I ask questions at my health appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I keep an infusion log.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I know what a 504 plan and an IEP are.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I have a plan for life after high school.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I know what I need to do for healthcare coverage after I turn 18.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I know what a co-pay is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I have paid a co-pay myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I have my own checking account with a debit card.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I order my own infusion supplies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I know what doctors and hospitals I can use in an emergency under my insurance policy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I have chosen a primary care doctor to take over my care from my pediatrician.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I know my doctor's phone numbers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I eat healthy foods and get exercise.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

“Can we still go camping?” The answer was yes, and that was the beginning of Kris’ education about living with a chronic disease. Shortly after Keegan’s diagnosis, she suspected her older son had the disease also. Tests confirmed her suspicions. To arm herself, she learned all she could about immune deficiency and eventually volunteered for the nonprofit Immune Deficiency Foundation. Today, Kris works as an IG specialist for NuFACTOR, a specialty pharmacy providing home delivery of healthcare products and services.

Kris says her sons have always been determined to not let CVID or any other health problems stop them from achieving their goals. In seventh grade, Keegan’s asthma was flaring up because of chronic infections. Defying his health problems, he decided to become a runner, and soon he was on the cross-country team. “I came to understand the need for a transition plan because I knew I wanted Konner and Keegan to be as happy and independent as possible,” said Kris. “I knew I wasn’t always going to be there for them. I had to be willing to let them make mistakes and learn while they were still at home. That wasn’t always easy, but it gave me more confidence that once they were on their own, they would do just fine.”

Both Keegan and Konner have high hopes for the future, but they also have some concerns. Keegan wants to run his own business, but wonders if he’ll be able to buy a health insurance policy. And, while it is not proven that immune deficiencies are genetic, it is highly possible they are. Both young men want to be married eventually and have kids one day. Of course, they worry about passing the gene to their children, who could be carriers even if they do not become ill, all of which requires additional thought and planning.

Today, there are many resources for young people with CVID as they plan for transitioning to adulthood, including their physicians, the Internet, national organizations and local support groups. Sometimes just talking with someone who is going through a similar situation can ease the stress and confusion.

For any teen, becoming independent takes planning and forethought, but for a teen with an immune deficiency, it is a more complicated process that should begin as early as possible. By a child’s preteens, a transition schedule should be made so the child can become prepared to independently manage his or her disease by age 18. And, as awareness grows within—and about—the immune deficient community, so do the resources for transitioning teens. ■

Looking for College Scholarships?

There are many scholarships available for students with conditions considered disabling. Here are just a few:

Immune Deficiency Foundation Scholarship

This one-time award is available to individuals diagnosed with a primary immune deficiency disease.

<http://www.primaryimmune.org/services/scholarship.htm> 800-296-4433

The ELA Scholarship

This scholarship provides financial assistance to women with physical disabilities who are enrolled in a graduate program in a college or university in the United States.

<http://www.ela.org/scholarships/scholarships.html> 626-398-8840

Bank of America Abilities Scholarship Program

These scholarships are awarded to students with disabilities who have a career interest in finance, business or computer systems.

http://www.scholarshipprograms.org/bada/bada_2005_ins.htm 864-268-3363

Foundation for Exceptional Children

The Stanley E. Jackson Award for Gifted/Talented Students is given to students with a disability.

<http://yesican.cec.sped.org/scholarship/index.html> 800-224-6830

Joyce Walsh Junior Scholarship for the Handicapped

This scholarship is awarded to disabled members of the National Federation of Music Clubs.

<http://www.mfmc.net/scholarships.html> 317-638-4003

Panasonic Young Soloists Award

This award is given to vocalists or instrumentalists under age 25 who are permanently disabled and interested in studying music.

http://www.panasonic.com/corp_cont/celebrating.asp 202-628-2800

Horatio Alger Association Scholarship Program

The Horatio Alger Association provides financial assistance to students who have exhibited integrity and perseverance in overcoming personal adversity and who aspire to pursue higher education.

<http://www.horatioalger.com> 703-684-9444

Central Intelligence Agency: Undergraduate Program

The CIA Summer Internship Program is open to undergraduate students, particularly minorities and people with disabilities, who have completed one or two years of college-level academic study.

<http://www.cia.gov/employment/student.html> 800-368-3886