

Adult Down Syndrome

Spring 2002

Editor: Brian Chicoine, MD

Update

Please join us in welcoming Janet Bilodeau, CNP, who joined our team April 1, 2002. She is a nurse practitioner who has already met and served a number of our patients. We are very happy to have her join us. (Janet describes a nurse practitioner's training and responsibilities in the next article.)

The Center has continued to grow and we now serve more than 1,500 adults with Down syndrome. As a result of this growth, it has been taking a long time to get an appointment, especially since we did not have a medical practitioner at the office 5 days a week. Janet's addition to our staff will help with these problems.

We apologize for the recent changes that have occurred in scheduled appointments. We anticipate that Janet's addition to our staff will improve service. In addition, we anticipate that we will be able to add, in the near future, some of the additional services that have been requested. We will provide more information as we work through the details on those services.

Congratulations

Adult Down Syndrome Center

The Adult Down Syndrome Center was recently recognized by Advocate Medical Group with an MVP award for Equality. The MVP (mission, values and philosophy) award is given annually in each of 5 categories: compassion, equality, excellence, partnership, and stewardship.

A patient's family wrote about us: "We are grateful for their vast knowledge about the person with Down syndrome. Everybody is always friendly and accommodating. They heal the body and the spirit".

We are grateful for the acknowledgement and will continue to strive to live this value in our Center.

Lutheran General Hospital

Advocate Lutheran General Hospital was recently ranked as the 10th best hospital in the United States. This ranking was for quality of care and was the result of a study produced by Consumer's Checkbook, a Washington, D.C.-based nonprofit consumer education organization.

Congratulations to Lutheran General. As medical director of our center, I would like to add my own additional recognition for Lutheran General. It is #1 in my book in health care for adults with Down syndrome by generously supporting the Adult Down

Syndrome Center and providing the fine care our patients get when admitted to Lutheran General.

Atlanto-Axial Instability

Many people are aware of the issue of atlanto-axial instability (AAI) in Down syndrome because of the requirement by Special Olympics to get screening neck x-rays. Atlanto-axial instability is a condition in which the first vertebra slips on the second. The real concern arises when the vertebra slips enough to compress the spinal cord.

For years, Special Olympics has required that people with Down syndrome get a pre-participation neck x-ray. The concern is that if someone has a "loose neck," then participation in certain sports could lead to a sudden, serious injury. Generally, if a person has AAI, then it is recommended that they not play contact sports, dive, do tumbling, or do the butterfly stroke in swimming.

The other situation in which screening is important is in a pre-operative evaluation. A person who has AAI may develop spinal cord compression in the operating room because of positioning of the head during intubation (placing of the breathing tube). A neck x-ray is advised before surgery for those who have not previously had one.

Whatever the reason for the slippage, when the vertebrae move far enough, the spinal cord can be compressed. This can cause weakness of the arms and legs, urinary and bowel incontinence, a change in gait, neck discomfort or a change in neck or head position. With progression of spinal cord compression, paralysis can occur. In some instances, the nerves that drive our breathing can be compressed, causing a reduced respiratory drive.

For years, we have debated whether we should do screening x-rays in people who did not have symptoms. However, as we see more and more older people with Down syndrome, we have discovered an important health issue. As people with Down syndrome age, some will develop degeneration of their joints. This is certainly not unique to people with Down syndrome. Many people develop joint problems with age. However, the neck seems to be particularly sensitive in people with Down syndrome. This has been manifested as an increase in slippage (subluxation) of the first and second vertebrae causing compression of the spinal cord. In addition, we have seen subluxation of the other vertebrae in the neck of some of our patients.

Nurse Practitioner

Janet Bilodeau, CNP

My name is Janet Bilodeau. Prior to coming to the Adult Down Syndrome Center, I worked as a nurse for 16 years at Advocate Lutheran General Hospital on the Physical Rehabilitation Unit. About five years ago, I decided to enroll at Loyola University to work on my Master's Degree. I love working with people, so I decided to study to become a Nurse Practitioner. During my clinical training at Loyola, I worked with many underserved populations in the Chicago area and on an Indian reservation in South Dakota. When the search for a Nurse Practitioner for the Adult Down Syndrome Center came to my attention, I felt that my nursing experience and clinical training would be a good match for working with people with Down syndrome.

So what do Nurse Practitioners do in caring for patients? A Nurse Practitioner is trained in examining, assessing, evaluating, and treating many health problems that people have over their lifetime. Some of the functions a Nurse Practitioner can perform include prescribing treatments and medications and making referrals to other healthcare providers. Nurse Practitioners can also perform many in-office procedures such as pap smears, incision and drainage, and mole and skin tag removal. If you have any questions about what a Nurse Practitioner does, please call me at the Center and I will be happy to talk to you. Thanks to all of you who have made me feel so welcome. I look forward to meeting all of you.

We have now seen about 15 people with Down syndrome who developed spinal cord compression because of subluxation of vertebrae in their neck. When the spinal cord is being compressed, the only treatment is surgical. The vertebrae must be adjusted away from the spinal cord and then stabilized so the corrected position is maintained.

In the past, surgeons have reported a very high rate of complications during and after the neck surgery. One study even quoted a 40% mortality rate. However, we have been fortunate to have a very fine surgical team as well as superb teams in the surgical intensive care unit and on the orthopedic unit. We have had no deaths related to this surgery. While there have been some complications, the rate is lower than previously described and we have developed an improved understanding of the potential problems.

Based on these findings, we have asked ourselves whether we should be doing screening neck x-rays regularly in our patients. At this point it is not clear. We do recommend annual physical exams to assess for changes that would be consistent with spinal cord compression. We also recommend bringing to our attention changes that could be caused by spinal cord compression: weakness of arms or legs, new onset of urinary or stool incontinence, complaint of neck pain, or change in position of the neck or difficulty holding up the head.

Dr. Mardjetko, the orthopedic surgeon who has performed the surgeries on our patients, is presently doing a study on orthopedic problems in adults with Down syndrome. He is doing a series of x-rays including neck x-rays. His goal is to assess 100 adults with Down syndrome and follow them over time. From this study and from our experience with our patients who have developed neck problems, we will continue to learn more about orthopedic problems in people with Down syndrome and identify appropriate treatments.

If you are interested in participating in the study, please contact Leonard at Dr. Mardjetko's office: 847-375-3071.

Advocate Medical Group is affiliated
with Advocate Lutheran General Hospital.
www.advocatehealth.com/amg

Memorial Donations

Thank you to all that support our work at the Center. Thank you to the families who have remembered us in memorials. We have received donations in memory of the following people:

Helen McGuire (Dr. Dennis McGuire's mother)

Daniel McNeil

Mary McNeil

Marge Rheume

Tony Rebello

Henry Tamanaha

Aya Yanase

Recurrent Boils

Recurrent boils are a common problem for adults with Down syndrome. The axilla (armpits), groin area, the buttocks, and the thighs are common sites where this problem occurs. We recommend the following:

1. Gently but thoroughly wash the area of concern daily with an antibacterial or anti-acne soap. A loufa sponge is often helpful.
2. Thoroughly rinse the area.
3. Gently but thoroughly dry the area.
4. Applying baby powder may help keep the area dry, particularly in hotter, humid times.
5. When a boil occurs, apply a triple antibiotic cream such as Neosporin.
6. A few studies have suggested that Zinc and Vitamin C may improve the immune function of some adults with Down syndrome. We recommend Vitamin C 1000 mg daily and Zinc sulfate 100 mg daily. This is in addition to a good one-a-day vitamin.
7. If the boils continue to be a problem, using the prescription soap Hibiclens on the problem areas has been helpful for some of our patients.
8. If the boils continue to be a problem, some of our patients have benefited from using a daily antibiotic (this is similar to the way acne is treated). A daily dose of amoxicillin, tetracycline, or other antibiotic may be helpful.



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