

A Coda shares insight – The Salk Institute

by Mary Thumann

When a parent has a stroke, it can be a frightening experience for the whole family. When the parent is Deaf, so many more issues are involved, and the family begins to feel helpless. Where are the resources for Deaf people dealing with strokes?? Where are the resources for the families trying to help in recovery??

My father had a stroke in 1997, and we received no information about possible resources. We accepted the minimal help offered by the hospital and therapists who, of course, did not sign. Fortunately for us, my father's stroke was mild, and we did not feel the need to investigate alternatives for him.

This year, my partner's father had a severe stroke. Just after the stroke, everyone in the family was searching for resources. Not surprisingly, we were unable to find much information. Our search for information resulted in support from the MotherFatherDeaf One.list where we were encouraged to contact the Salk Institute. In addition, one sister had previously worked with the Salk Institute on another research project related to ASL, and a few other people in the Deaf community mentioned the same potential resource. What a relief it was to know that someone out there might be able to help!

After meeting Dr. Greg Hickok and Raylene Harris (the two researchers who worked with Dad) and hearing about the program, we decided that this information should be shared with others, especially Codas who may end up caring for a parent who has a stroke. The Salk Institute does much more than research Deaf individuals who have had strokes, so I encourage everyone to check their web site.

The family arranged to have Dr. Hickok and Ms. Harris come to the rehab center where Dad was staying. (They are willing to go anywhere in the country to gather research information on Deaf people who have had a stroke.) We would not have been surprised if they had arrived, gathered their research informa-

tion then left, but this is not what happened. Dr. Hickok and Ms. Harris met with Dad as soon as they arrived in town, and that evening Dr. Hickok met with the family. One of the things that impressed me most was the genuine respect displayed by Dr. Hickok and Ms. Harris both for Dad and for the whole family. They exhibited concern and interest and were clearly supportive of the family and our needs. We asked many questions about the research that has been conducted and the type of information they hoped to gather from Dad's case. (We learned that the majority of the Deaf people they study have been dealing with their stroke two years or more before learning about and contacting the Salk Institute.) Dr. Hickok explained the various tasks that would be conducted during the interview with Dad and assured us that if Dad was not able to complete all the tasks in the interview, we should not be concerned at this point. He also explained that they typically interview a person for four hours (broken up into segments) or until the person begins to show signs of being tired. Although their goal is to gather as much information as they can, they strive to protect the dignity of the individual and the family.

After the interview and videotaping was complete the two researchers met with the family again to talk about their impressions. Dr. Hickok was very reassuring and offered to talk to any doctors, speech/language therapists or anyone else who would be working with Dad. Dr. Hickok explained that although they have not done research on treatment, they are available to talk with professionals involved in a case about effects of stroke on the people they have studied. They are knowledgeable about different techniques that seem to help in recovery and are willing to discuss those techniques with the therapists and medical professionals. I can't imagine anyone being more supportive than these two were, especially in such a stressful situation. The researchers at the Salk Institute are very aware and respectful of Deaf Culture and issues related to communication. The interviews are conducted by teams of two people, and the teams always include a Deaf researcher.

One of the goals of the Salk Institute, as stated on the web site, is to increase awareness of sign language and the special needs of Deaf with stroke or other types of brain injury. The Salk Institute Web site has much more information regarding their programs including articles that have been written, annual reports, and other interesting information. Please visit the web site or contact them for more information. When the Salk Institute has job openings, they often look for Deaf people or Codas to do research or interviews, so be sure you contact them if you're interested! They are always looking for assistance in their research and, because they say it better than I could, I quote the following (taken from the web site <<http://lcn.salk.edu>> under American Sign Language) "You Can Help! There are many ways you can help increase awareness of Sign Language and the Deaf. If you or someone you know has had a stroke or other type of brain injury, please contact us at the address or phone number at the bottom of this page (collect calls are fine!). We will send you more information about our studies and about how you can join in. We travel all over the country to interview with participants, and we pay \$10.00/hr. All interviews are done by Deaf researchers, and all the interviews and requests for information are kept confidential. Another way you can help is by spreading the news about our studies. We are happy to provide you with information about our research that you can distribute at gatherings of Deaf in your area. Just contact us at the address or phone number below. The Deaf community has been very important to advance our studies and we have made many friendships. We hope that with your help our research will benefit future generations of Deaf in this country and all over the world."

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