



Newsletter Spring 2004

SNSC-UV News

SNSC-UV is celebrating its 25th year during 2004! We began the celebration at our Annual Meeting in November, 2003 with several of the founding members, who talked about the first meetings of the group at the home of Geraldine and Bill North in Hanover. The meetings not only provided connections with other parents; the gatherings also brought parents and professionals together to think of and find ways for children with **any** special need to succeed at home, at school and in the community. Parents came from New Hampshire and Vermont Upper Valley towns to meet with other parents, to get and give support, and to learn from each other.

Fond memories were recalled: of the tireless work of Trudy Hemelgarn, who has since passed away; of the first real office, in space arranged by Dr. George Little on the old Mary Hitchcock Hospital campus; of the excitement of the first grant written and awarded.

Many thanks to Geraldine North, Connie Bardorf, Joanne and Bob Scobie, Pat Martin, Bobbie Gross, Karen Currier, Trix Officer and Bev Parry for sharing their memories of the early years of the organization, the vision that inspired its beginning, and the years of growth between then and now.

During the business portion of the meeting, we all thanked Dr. Douglas Williamson for serving on the Board and as its President. Doug is now the President of the physician's group at Alice Peck Day Hospital.

We also thank Elizabeth Larsen, Nicholas Burke and Tony Grizzaffi for their years on the Board.

Gifts for the Respite Program

For about 50 years, there has been a Holiday Dance in December in Hanover. Since 1991, the Holiday Dance Committee has been raising money to support one local non-profit program a year. In September the Respite Child Care Program received a call asking if we would be interested in being the recipient of this year's proceeds. With an enthusiastic answer of "YES!" it was set in place. Over the next few months the Respite Program heard from various people on the Holiday Dance Committee to discuss plans for the upcoming event and how the Respite Child Care Program could contribute (providing program information to include with invitations, providing a display to have at the dance).

On December 12, 2003 the dance took place at the Collis Center on the Dartmouth campus. About 167 people attended with a total of \$3,530 being raised. Individual donations were almost \$2,000.00 and the Holiday Dance Committee donated \$1,565.00. The money raised will be given directly to families who need assistance paying for respite. This donation will be of significant help to families of the Upper Valley who are in need of respite. We appreciate all of the hard work and the thoughtfulness of the Holiday Dance Committee. They put together a wonderful event the proceeds of which will be touching the lives of many families.

Many thanks to the Holiday Dance Committee for such a wonderful gift. We are truly grateful.

*Nicole Demers
Respite Child Care Program Coordinator*

New SNSC-UV Board members Hope Charkins of Norwich and Ellie Pierce of Hanover were voted in and join the following very special group that makes up the Board of Directors: Toni LaMonica, President; Dr. Steven Atkins, Vice-President; Phyllis McKenna, Secretary; Kathy Marshall, Treasurer; Ann Christiano, Karen Currier, Maggie Pyer and Dr. Andrew Werchniak. Thank you all for your time and efforts on behalf of our now 25 year old organization!

The Respite Child Care Program was also the recipient of a memorial donation in the memory of John Williams, father of Lori Harris of Hanover.

Thank you to Drew and Claire Nelson, owners of Board and Basket, for donating the proceeds of a knife sharpening clinic to Special Needs Support Center Of The Upper Valley. The knife sharpening clinic was held at Board and Basket on March 27, 2004. The event raised over \$200.00 and will benefit many families throughout the Upper Valley. We are grateful to Board and Basket for their generosity.

KATIE BECKETT WAIVER MEDICAID

Hearings are being held throughout the state in January to provide citizens the opportunity to discuss the waiver with representatives from the Office of Health Planning and Medicaid. It is important that parents, school and medical personnel, and health care vendors attend.

Parents who currently receive Medicaid insurance for their children either through HC-CSD (The Katie Beckett Waiver) or through needs based Medicaid need to be conscious of deadlines for filing re-determination papers.

GET YOUR PAPERWORK COMPLETED AND IN BEFORE THE DUE DATE. If you lose (or lose track of) the paperwork you may lose the benefit.

- Make copies of all materials
- Keep a log of all phone calls
- Follow up after sending the materials to make sure that they were received
- As an extra precaution consider faxing materials to the district office-call 1-800-982-1001 and ask if the fax machine is working and for the number. You can zero out when you get the options and ask the receptionist for this information.

The latest edition of the New Hampshire Challenge, <http://www.nhchallenge.org/> contains

Happenings

It may have been a cold February night outside, but the dance hall sizzled within at the Happenings Valentine event. Local high school students, youth group members and rocking parents joined the Happenings crowd for yet another fun and anything but subdued dance. DJ Brian Warren kept the dance floor filled while dancers were surrounded by glittering mini-lights and Valentine decorations designed by Karen Currier. On their way out, people are already asking about the next dance, so here it is: May 7. This will be our Spring Fling, and if you'll recall, our last year's Spring Fling was canceled due to snow! That is not going to happen this year.

The Happenings Planning Committee met in early March to discuss activities for the coming months. We are planning to have three cookouts this summer, one in each summer month. Sue Rump volunteered to reserve a space for the June cookout at the Union Village Dam. If you have ideas of locations for the other months, please call SNSC-UV at 448-6311.

A karaoke night will start off the new school year. This is something that the teens and young adults have been wanting and may well become a regularly scheduled activity.

We would like to have one Friday night in each month on the schedule as a game night or a

important information on upcoming hearings on the Katie Beckett Waiver. There is an interview with the new commissioner, John Stephen. Page eleven of the Challenge addresses questions that you may want to consider, especially if you are passionate about retaining the waiver and would like to testify at the upcoming public hearings.

movie night. Any ideas for a location?

Advocacy Anyone?

by Maryellen Sullivan

Here's the skinny: I am writing to make a case for and multiply the numbers of advocates working with parents of children with any special need. You'll notice that I did not put an adjective in front of advocate; I didn't say educational advocate, parent advocate, paid professional advocate. I didn't put an adjective in front of advocate because there may not be a specific, trained advocate available to many parents in New Hampshire. And in the absence of a trained advocate, a friend, relative or professional working with the family can act as an advocate, or support person, for parents when they attend school or medical meetings.

What does an advocate do? Well, he or she provides an extra pair of eyes and ears, for one thing. An advocate who is not emotionally involved can concentrate on what is being said, can bring up an issue or concern discussed with the parent but which has not come up in the meeting and, in the case of an educational advocate familiar with education laws, can explain and clarify the special education and IEP process for parents. "What you don't know can't hurt you" does not apply when attending a school meeting where laws dictate the process..

It's no secret that parents of children with any special need have some additional demands, tasks, whatever we would like to call them. There are more meetings, educational and medical; there are more resources to discover; there is more time to be spent on the child, whether it involves medical care, behavior issues or academic support. If the parent is lucky, there will be someone living nearby who has faced

Family Support Council News:

The Council is looking for new members who are interested in representing the needs of the families in the region and participating in the work of the Council It's a small but strong group who would like to share their mission with others. The Council is working closely with UDS staff to increase communication and better address the evolving needs of families. SNSC-UV staff carry out some of the work of the Council-Big Brother/Big Sister, Happenings, the social skills groups, educational advocacy, information and referral, the resource library, and specific gatherings and trainings as directed. The Council welcomes feedback from parents regarding these programs.

Families seeking specific support through Council grants will be asked to complete the new Individual Family Support Plan. This plan is now required by the State and it provides a vehicle for the Council to have hard data relating to the needs of the region.

At the November Council meeting the members voted to participate in a statewide program of respitality. Respitality is a combination of respite and hospitality. Hotels and inns in New Hampshire donate accommodations to company named Respitality by Design. Agencies contract with this company to provide a maximum of two nights per calendar year to eligible families. UDS eligible families may contact Tara at 443-4109 or tara@uds.org for more information.

The Council has had representation at UDS task force groups addressing respite and quality. The Council will be kept informed on waiting list issues. Council members receive monthly reports from both UDS and SNSC-UV. One member

these challenges and who can provide a shortcut in some of these areas. But what is the probability that there will be a support like this at the backyard fence or even in the neighborhood?

I attended a meeting recently where some parents talked about the fact that it took them a full year of school meetings before they started to feel comfortable enough to ask questions and raise issues. And when one is not clear on the process and unaware of one's position and rights, one tends to be less trusting of what is happening. Sadly, some parents have no idea that there are people who might be there to support them, to serve as an advocate.

New Hampshire has a wonderful educational advocacy training organization, the Parent Information Center, which provides advocacy training at no cost to parents and others who are willing to volunteer as advocates. This nearly 50 hour training covers educational rights, the special education process, the writing of the IEP (Individual Education Plan), resources, parent/professional communication and other topics. At the end of the training, a person is well-prepared to attend school meetings on behalf of the children who will be receiving services.

An advocate is not an adversary. An advocate should be a welcome addition to the IEP team that is working together to provide a free and appropriate public education (FAPE) to the student. Parents are team members and all team members are equal. If a decision is made, and a parent does not really agree with that decision but does not feel that he or she can disagree, then one team member will leave the meeting feeling unheard, invalidated and perhaps resentful. An advocate can be of help as the meeting proceeds, by looking at the parent and asking what the parent thinks of a school's proposal. This sounds so basic and unnecessary, but often the question would otherwise go unasked. Or a parent, the newcomer to the process, will feel uneasy about contributing his or her opinion.

So, if you are a parent, consider investing the

represents the region at the statewide Council. We do very well for a small region—our voice is heard and respected in the state.

The Council has a goal to focus resources on social and recreational activities for those over age twenty-one while it retains a concern for the needs of other age groups. There was an astounding response to a recent survey sent out by UDS. Over one hundred surveys were sent out with a response of about fifty-five. The challenge will now be to create opportunities to address the expressed needs in the current economic environment. If anyone is interested in hearing more about this, sharing his/her thoughts, or becoming involved please contact UDS at 448-2077.

Kids on the Block Donate Performances

The Kids on the Block puppet troupe received two generous donations within the past six months. When we asked how they would like that money used, they suggested offering some free performances to schools in April and May.

Philip Eller mailed notices to local schools to let them know that the Kids would be happy to make an appearance, and shortly thereafter the puppets' calendar was nearly full!

SNSC-UV is so fortunate to have six dedicated volunteer puppeteers who travel here and on each Thursday during the school year promoting an awareness of differences, social issues and abuse. Our thanks go to Ann Justice, Coordinator, Bev Strout, Merry Converse, Barbara Payson, Judy Thrasher and Barbara Whitman.

If you or someone you know has a child with a chronic medical condition look to the NH Partners in Health Program here at SNSC-UV. We provide free supports to children and families with a variety of medical needs regardless of income or insurance. We offer coordination to local and state resources, information and referral, advocacy, family support, and

time in becoming an advocate for your child and perhaps to help others in your school or district. If you are a professional, consider the training so that you will be more informed as you attend meetings with parents.

Reprinted from a 2003 eein newsletter

ARE YOU INTERESTED IN HAVING YOUR CHILD, 8-14 YEARS OLD, BE PART OF A SOCIAL SKILLS GROUP THIS SUMMER? IF SO, CALL PHILIP AT SNSC-UV, 448-6393.

flexible funds. Call Katie Ouelette at 448-7108 for more information or to enroll.

Sibshop, a fun gathering for 6-12 year olds who have siblings with special needs, will meet on Saturday, June 5.

Please call Philip Eller at 448-6393 or Toni LaMonica at 653-1488 to register.

Sylvia Dow has organized a group of parents who are interested in finding independent housing options for their children with special needs. The second meeting of the group will be on April 12 at 7 p.m. at SNSC-UV, 12 Flynn Street in Lebanon. Please call Sylvia at 632-7672 or SNSC-UV if you are interested in attending!

Recognizing Reuben

We are so lucky to have Reuben the pug as a regular volunteer at SNSC-UV. Reuben is always at the door to greet visitors, and when they are inside, he is there to "break the ice," to comfort, to amuse or to play. Recently, a parent told Katie Ouelette, who shares Reuben with us, that being in the office with him was the only cheerful experience of her week. Go, Reuben!



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Read Past Issues

The SNSC-UV homepage address is www.sncs-uv.org