



Connecting with Those Who Understand: The Importance of CdLS Support Groups

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I had the privilege of attending the 2018 CdLS Family Conference in Minneapolis in June. This was my second time attending Conference, and I was once again amazed and humbled by the experiences I shared with our wonderful CdLS families and our committed Foundation staff and volunteers. During one of my presentations at Conference this year I became unexpectedly ill, leading to an abrupt disruption of my presentation. The CdLS families and staff who were in attendance took immediate action to help and care for me. Several families stayed by my side until I was well again, and no one was upset or frustrated that the presentation they came to see was unexpectedly interrupted. Going through this unforeseen experience at Conference reminded me of what I already knew...that our CdLS families are some of the most empathic, selfless and giving people I have ever had the privilege of knowing. Their response to me was a testament to the importance of supporting one another through difficult and unpredictable circumstances.

Our biennial Conference provides many valuable resources and opportunities for the families who attend, including medical and behavioral health consults, and diverse presentations and workshops that address pertinent needs. One of the most significant components of Conference is the direct support provided for families who attend. This year's Conference included various support groups, including those for mothers, fathers, grandparents, and for adults with CdLS.

The Significance of Support Groups

Support groups provide individuals and families with a unique platform for sharing their stories and experiences. For many in a specific disease community, emotional needs are not always addressed through routine medical treatment, and sometimes our own families are not able to provide the emotional support or understanding we desire. Support groups involving others in the CdLS community may help fill the gap between medical treatment and the need for emotional support.

Some of the primary benefits of support groups include: (1) Solidarity- realizing that you are not alone and that there are others who share similar struggles, feelings, and experiences is extremely beneficial, and can help reduce isolation and fear; (2) Emotional Expression- support groups can provide the emotional safety for one to be open and expressive without worry of being judged or not being understood; (3) Transformation of Information- support groups are an effective way to share and receive helpful information and educational resources, and to distribute new ideas; (4) Stress Reduction and Coping Skills- support groups help people work





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through stressful situations and difficult emotions while simultaneously receiving support and encouragement from other group members; (5) Enhanced Self-Awareness- we can develop new and helpful perspectives and insights through participating in a support group and learning from others; and (6) Hopefulness- being with others who truly have empathy and understanding for our situation can help instill hope for even the most difficult circumstances. The CdLS Foundation continually strives to respond to the needs of families by providing relevant and appropriate levels of support for caregivers, family members and individuals with CdLS. If you have not yet had the opportunity to participate in a support group, consider looking into it as another element of your care. If you have not yet utilized support services from the Foundation, or feel that it is time to seek new and/or additional services, please consider exploring what the CdLS Foundation has to offer.

Having the opportunity to be at Conference again this year was further confirmation of just how vital it is to be connected to others who share our experiences, and how offering support groups can lead to enhanced self-care, advocacy and so many other helpful outcomes. For more information on family support and other services provided by the CdLS Foundation, visit <http://www.CdLSusa.org> or contact Deirdre Summa, Family Service Manager, at familysupport@cdlsusa.org.

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