



# Newsletter



**Fall 2012**

## Welcome To GAN!

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***GAN members are a vital resource for autism  
... and each other!***

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**Comments? Tips?  
Suggestions?**

To send in comments,  
suggested topics for our  
next newsletter, or  
grandparent tips, please  
[email us.](mailto:info@ganinfo.org)

Join Our Mailing List!

The **Grandparent Autism Network**, an all-volunteer 501(c)(3) nonprofit organization, was founded in 2006 in Orange County, California to bring information and support to local grandparents of children with autism and their families. As the incidence of autism has risen to epidemic levels, GAN has received hundreds of membership requests from grandparents residing outside of Orange County. **In order to increase support for more families, GAN's board of directors voted to provide cost-free "e-membership" in GAN to grandparents nation-wide.**

GAN's newsletters focus on issues that impact grandparents and offer suggestions about how you can help to develop new autism supports and resources in your own community. While GAN does not have chapters in other areas, GAN's website, [www.ganinfo.org](http://www.ganinfo.org) has information about autism presentations, advocacy issues, beneficial programs and projects, and tips and recommendations from other grandparents. ***You are welcome to share our resources and replicate everything with the exception of our trademarked name and GAN logo.***

***We know that the best information we share comes from grandparents and we welcome your feedback and suggestions about how we can increase support for you and your family.***

## **How Can You Find or Start a Local Grandparent Support Group?**

***This the most frequent inquiry GAN receives. Support groups are easier to find or establish in larger cities, however, grandparents residing at a distance from autism centers often ask how they can establish a support group in their community. The following suggestions may be helpful in either situation and should enable you to organize groups and presentations cost-free.***

- *Autism Speaks* has a Resource Guide that lists organizations, programs and services in every state. You can find it [here](#). If *Autism Speaks* has a WALK committee in your community, contact the leader. churches that serve "special needs" families.
- In order to find an existing group, you can *Google* for local support groups, or you can go to the [website for meet up groups](#) That site will also help you [create an internet web link](#) so people will find your group after you start it. You can get answers to questions about how this site works [here](#).
- If you live in the same community as your grandchild, ask his parents if they have met other families that have local grandparents. They may see grandparents at school events, occupational or speech therapy sites or they may belong to a parent support group where they can ask about other grandparents you could contact.
- Call local churches, hospitals, pediatricians, colleges, autism agencies, service providers or the special education office in your local school district to ask if a support group exists in your area. If not, request that they ask the families they serve to provide contact information for grandparents who are interested in a peer support group.
- Print a simple 1 page flyer requesting other grandparents contact you if they want join a support group. Provide flyers for the sites listed above, You can also post flyers in libraries and distribute them to agencies that serve families with autism such as Easter Seals and United Cerebral Palsy. Ask your local newspaper to print an article about your efforts. If there are local health resource fairs, distribute your recruitment flyers there.
- When you have identified 6 or more grandparents, host a meeting in your home or a church, synagogue, senior center, public library, school district building, or a conference or

community room that is cost-free. You can also meet in a restaurant for a "no host" meal, dessert or just a beverage.

- Discuss what kind of support group your members want. You may only want to share personal experiences and suggestions at meetings. If you are geographically isolated from autism resources, you may want to review autism books or online information together. The UC Davis MIND Institute's website provides [video links](#) to many excellent presentations. There are other sites where you can access professional speakers on topics of interest, as well. Use a search engine to locate resources on topics of most interest to the group.
- Determine the timelines when your group will meet. GAN's best attendance is at meetings scheduled weekdays from 10 a.m. to noon or from 1:00 p.m. to 3:00 p.m. A few meetings have been planned for 6:00 p.m. to 8:00 p.m. to accommodate to members who are employed.
- If your group is interested in advocacy, projects to help families or social events for all 3 generations, you will find many suggestions on the [GAN website](#).
- Ask each grandparent to take a role in organizing the group. You will need volunteers to manage a member database and to send meeting notifications or post them online. If you want to have professional speakers at meetings, you will need help to identify and confirm qualified speakers and cost-free meeting sites. As your membership grows and becomes more active, you will be able to identify additional areas for volunteer participation.
- Prior to presentations, recruit some volunteers to arrive early to post signs from the parking lot to the meeting site. You may also need help setting up (and cleaning up) seating and tables. If desired, bring donated refreshments and paper goods. If you leave the event venue in good condition, you will likely be welcome to reserve it again, at no cost.

## How and Where to Find Autism Speakers

- *All presentations should be evidence based or focus on best practices information if they relate to autism treatments.* Identify a cost-free, well qualified speaker for a topic of interest. Doctors, psychologists, special education teachers, attorneys, dietitians, social workers, autism service providers, successful adults with autism and parents who have older children with autism are all good prospective speakers. You can determine topics with them. For some ideas, check out GAN's website list of [Events and Past Events](#) . Schedule time after presentations for interactive *Question and Answer* periods.
- ***Important: Avoid engaging any speaker who is self-promoting or marketing a particular autism service or product. You want to educate about autism and learn about various treatments and interventions ... not advocate for***

## **To Tell or Not To Tell**

***David J. Monkarsh, Ph.D. is a Clinical Child Psychologist who has specialized in the therapeutic treatment of individuals with high-functioning autism and Asperger's Syndrome since 1980, in Orange, California. This article focuses on a difficult family issue that confronts many of us and his advice about how to best maintain a positive relationship with our grandchildren's parents.***

The birth of a child is a life-changing event for every family. Hopes and dreams for the future are being created that very first day, and the tempo, tone, and nature of a family is forever changed by the birth. Parents, siblings, grandparents, and other family members immediately begin to emotionally connect to the new infant. A lifelong place in the family's evolving future is created in both the hearts and minds of all extended family members.

As young children grow and change, it's not always evident to all family members that a child faces developmental challenges. Primary caregivers are prone to compensate for a child's social and communication skill deficits by working harder to assure that emotional and social connection are achieved. Children with developmental disabilities train their parents to anticipate their wants and needs, and a sense of shared and reciprocal interaction emerges as parents work over-time to establish and sustain a feeling of connection that is sometimes one-sided in nature. All parents who are responsible for a child's day-to-day life within the home participate in this process, and it's not always easy to recognize a child's diminished capacity to initiate and sustain interaction through his or her own efforts.

Grandparents who do not live with their grandchildren often bring a different perspective to their appraisal of their grandchild's developmental process. While connected at the heart, they have a historical perspective of watching a child grow and mature that informs their view and understanding of their grandchild. Instead of over-extending themselves to assure that reciprocal interaction emerges with their grandchild, grandparents are often the first to recognize when a child lacks age appropriate social skills or the capacity to engage others effectively.

***None of us are able to hear anything from others that we don't already know or recognize for ourselves. Truths that are spoken too soon often fall upon deaf ears. Intergenerational breaches in relationships may easily arise when grandparents share thoughts and concerns with adult children who are unaware or in denial of their child's developmental struggles.***

How and if it's beneficial to raise concerns about a child's developmental difficulties often comes front and center for grandparents who have a grandchild along the autistic spectrum. The initial issue that arises is not related to the possibility of an autism

diagnosis, but rather it focuses upon the nature of the relationship a grandparent has with his/her adult child. ***If there is a framework for open and honest communication that has been built during earlier times, then it becomes possible to discuss concerns about a grandchild's development. If communication is strained between grandparents and their adult children, then vigilance and sometimes silence is called for.***

The prospect of sharing unsolicited advice or information improves significantly when grandparents acknowledge and respect their adult child's primacy as their grandchild's caregiver. Being able to play a supportive and active role in helping promote understanding and intervention strategies over time depends upon a grandparent's capacity to successfully contend with his/her own feelings of helplessness and urgency. ***Maintaining regular and consistent access to a non-diagnosed grandchild with autism often requires both compassion and self-restraint. Respect for an adult child's understanding and personal boundaries helps promote the capacity to actively participate in the growth and nurturance of a grandchild with special needs for many years to come.***

## **Plan Ahead for Holidays**

Sometimes families find it difficult to share holidays together because a child's autistic behavior is misunderstood. The parents of the child with autism may receive undeserved criticism from family members about their inability to control their child. There are many things you can do to prevent this from happening and to make the holidays more comfortable and supportive for your grandchild with autism and his parents.

Old holiday traditions may need to be modified to make family gatherings more inclusive. ***Begin now to prepare your home and family members.*** Visit GAN's website for some practical holiday tips. In addition to gift ideas, there are excellent suggestions shared by other grandparents, to ensure that everybody will enjoy the holidays.

## **GAN Invites Your Feedback**

This is our first national quarterly e-newsletter and we welcome your questions, comments and recommendations for future issues. Together we are ...

***a vital resource for autism ... and each other!***

Best regards,

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