

NYS ID/DD NURSES ASSOCIATION NEWSLETTER

Vol. 26, Number One

Winter 2019

President's Message



Hello Fellow Members:

I hope you all had enjoyable holidays.

A new year is upon us and with that comes a renewed look at our Association---where we have been, where we are now and where do we want to go. Our mission is to educate nurses in the care of the individuals we

serve and to provide information on new developments in care. We do this through our annual conference, zone meetings, networking and supporting each other across the state.

Each of you can enhance what you learn and gain from your membership by becoming more involved in your zone or on the state level. Ask your Zone Officers about being more involved within the zone. Feel free to contact me by email if you would like to be more involved, have questions or have suggestions. I would love to hear from you. We are looking for members to assist on the New Nurse Curriculum Task Force. Meetings are held by phone conference. I'm sure many of you have great ideas for input. Please contact me if you would like to join the task force.

I'm looking forward to sharing our progress this year with each of you and hope that you will be part of our forward movement.

Darlene dlangkau@hotmail.com



March 19 Certified Nurses Day!

Congratulations CDDNs!

Gallup Ranks Nurses Most Honest and Ethical

More than four in five Americans (84%) again rate the honesty and ethical standards of nurses as "very high" or "high," earning them the top spot among a diverse list of professions for the 17th consecutive year. Gallup reports, "With the exception of one year, 2001, when firefighters were on the list after the 9/11 terrorist attacks, nurses have far outpaced all other professions since they were added to the list two decades ago."

"Every day and across every health care setting, we are on the frontlines providing care to millions of people. Nurses' contributions to health care delivery, public health challenges, natural disaster relief efforts, research, education, and much more, are unmatched and invaluable," said ANA president Pamela F. Cipriano, PhD, RN, NEA-BC, FAAN. "These results are a testament to nurses' impact on our nation."

WEBSITE REPORT-NYS ID/DD NAWeb Address: www.nysidddna.org

The updated website is now in place. Please check it out. A lot has been done to make it easier to navigate. The ability to sign up for membership has been streamlined to have a direct connection to our management organization. Signups for the annual conference will be easier also. Let us know what you think.

FACEBOOK-NYSidddna

There is direct connection now between the website and facebook. Look on the website homepage and note the small "f" at the top of the page. Click on that to go right to our facebook page.

tpotocar@slnysarc.org. Trish Potocar, RN, Website Chairperson

The New York State Intellectual Disabilities/ Developmental Disabilities Nurses Association (NYSID/DDNA) was founded to promote Intellectual and Developmental Disabilities Nursing as a specialty area of practice.

The Association continues to support its members' activities in nursing law, education, research and practice.

Zone Reports

Zone 1-(St. Lawrence, Franklin, Clinton and Essex Counties)

Zone 1's next meeting is planned for March. We are checking options for presentations. Neurocrine who provided the speaker on Tardive dyskinesia has offered speakers on other topics. For information contact Trish Potocar tpotocar@slnysarc.org or Karen Jarvis kjarvis@slnysarc.org

Trish Potocar, Co-Chairperson, Zone 1

Zone 2-(Jefferson, Lewis, Oswego, Onondaga, Oneida, Madison and Herkimer Counties)

Zone 2 is planning on having a meeting on March 29 at Liberty Resources. More information on time and address will be forthcoming. Zone Officers are currently planning the remaining meetings for the 2019 year. If you have any suggestions on topics or speakers you would like to see covered in our meetings, please contact Amanda Aiello (aaiello@archerkimer.org), Melissa Britton (mbritton@liberty-resources.org), or Iellan Rice (irice@elmcrest.org).

Amanda Aiello, Chairperson

<u>Zone 3</u>-(Hamilton, Fulton, Warren, Washington and Saratoga Counties)

Zone 3 is actively seeking members who might be willing to consider co-chairing the Zone or working with one of the officers for planning and coordination our 2019 meetings. Unfortunately, activity among members has dropped off over the past 2 years, and we would love to revitalize the zone with improved attendance. There are also several new nurses working in Zone 3 throughout our many sister agencies and we would love to reach out to them.

Those who are interested in attending should reach out to Anne Payette at hansona2001@yahoo.com.

Zone 4-(Montgomery, Schoharie, Schenectady, Albany, Otsego, Delaware, Greene, Rensselaer and Columbia Counties)

Our December meeting was hosted by Michelle Hiscock at Living Resources on 12/14/2018. Ester Horowitz, from United Concierge presented on the use of Telemedicine. Living Resources also provided a buffet luncheon, which was sponsored by United Concierge for all attendees. This presentation was well attended. We also held our quarterly meeting, with a raffle & had some holiday trivia fun as well. Zone Reps were also elected.

Our plans for 2019 so far include:

- March 19 meeting hosted at Rensselaer ARC. Still working on final details but hope to have presentation on new assessment tool & drug for treatment of Tardive Dyskinesia. Watch for email flyer to come with final details.

- June meeting TBA but to be hosted by Oneonta ARC
- August meeting TBA but to be hosted by Springbrook.

More information to come by email as the dates get closer.

Mary Jean Keegan, Zone Representative.

Zone 5-(Sullivan, Ulster, Dutchess, Orange, Putnam, Rockland and Westchester Counties)

We did get together the end of last year but unfortunately an email glitch caused the message not to be delivered to many members. We will be getting together in March. Notice will be going out. Zone Representative Sandra Mellion (914)907-3719 sandramellion@gmail.com

Zone 6-(Nassau and Suffolk Counties)

The Zone remains very active and continues to recognize the importance of recruiting new members to the organization. We continue to encourage our members to achieve DDNA National Certification as C.D.D.N. (Certified Developmental Disabilities Nurses) to highlight our very specialized area of ID/DD Nursing and improve care to the men and women we support. Our members value and embrace the importance of continuing education in our profession.

Our annual Holiday meeting was held at Jake's 58 Casino in Islandia. We shared some good conversations with all those who were able to attend. After our dinner we all ventured into the casino to try our luck! It is always nice to get together during the holiday season with our friends and colleagues. We miss all those who were not able to attend and hope to see everyone at our quarterly meetings.

Our upcoming meetings for the year 2019 are as follows:

March 12th 3:00-5:00 pm to be held at UCP (Save the Date/Address to follow) - Guest Speaker will be Karleen Haines RN and will be speaking on Managed Care.

June 18th 3:00-5:00 to be held at Life's Work in Deer Park. Guest Speaker will be Perry Cyprus who will be presenting on the annual Diabetes update.

October 22nd 3:00-5:00 (location to be determined) Guest Speaker will be Fred Wetzel who will be presenting on RN vs LPN December 10th - Annual Holiday Party - Details

and Location to be determined

The Zone's mission for our meetings is to bring in informative and interesting speakers and offer educational opportunities to our members to increase the quality of services we provide to those we support. Our meetings and Zone membership

Zone Reports Continued

serve as an opportunity for camaraderie and information sharing, facilitating a partnership in best practice, and most importantly.....fun. Please feel free to contact any of our Zone Officers for information on Zone activities and meetings.

Officers:

Co-Chair: Patty Brunetti RN, QDCP pbrunetti@lifesworc.org 516 554-3012 Co-Chair: Mary Sherry RN, QDCP

marysworld7@gmail.com

Zone Representative: Laura Sardinia-Prager PhD, RN, CDDN, QDCP laura.Prager@liu.edu 516-741-

9000 ext 7460

Treasurer: Pat Ruckel MSN/MHA, RN, CDDN, QDCP prucke@phpcares.org 516 272-2982 Corresponding Secretary: Cathy Duijnisveld RN, QDCP cduijnisveld@familyres.org 516 297 7233

Cathy Duijnisveld, RN, QDCP cduijnisveld@familyres.org

<u>Zone 7</u>-(New York, Richmond, King and Queens Counties)

Zone 7 is alive, well, and now thriving! The Feb. meeting saw a large attendance with good variety from different agencies. Our membership is now up to 44 and growing each month.

At our March 11 meeting, Lieutenant Corando and her team will be able to train and register our Zone 7 nurses, and any other nurse that you invite to our meeting, on Emergency Responder. Again, the meeting is March 11th at 463 7th Ave...17th floor from 1230 to 230pm. Contact Gale Glasgow at GGlasgow@sus.org to register.

Zone 8-(Niagara, Orleans, Genesee, Wyoming and Erie Counties)

Zone 8 has been anticipating their Holiday gathering to be held on February 7th. Members participate in dinner and a gift exchange while simply taking a break from the hustle of the holidays. Our meetings are held the second Thursday of the Odd months at 6 pm. All are welcome to join us at the 7 Community Dr. location.

Linda Cultrara, RN, Zone 8 Secretary

Zone 9 & 11- Zone #9 (Chautauqua, Cattaraugus, Steuben and Allegany Counties) and Zone #11 (Monroe, Wayne, Ontario, Livingston, Yates and Seneca Counties)

Zone 9&11 meets in the Rochester area. We are currently looking for a new zone treasurer; anyone interested can contact Edie Smith, zone secretary, or Mary Ellen Stambersky, zone president. The zone officer positions of secretary and president are up this year, and we are seeking any interested members.

The final meeting for 2018 was held in November at Starbridge Inc. Guest speaker was Crystal Kelly MSN, APRN, the Clinical Practice Medical Science Liaison for Neurocrine Biosciences, Inc.; she spoke on Tardive Dyskinesia. Crystal Kelly works in N. Carolina in a psychiatric private practice and flew in to speak at our meeting. Focus was on tardive dyskinesia, review of clinical data, and the first FDA-approved treatment for TD in 2017.

The 2019 Meetings are scheduled for May 7, June 11, and October 8, all 1-3pm. They will be held at Starbridge, Inc. in Rochester.

Officers:

Mary Ellen Stambersky, Zone President, mstambersky1@rochester.rr.com Edie Smith, Zone Secretary, Edie.smith@cayugacc.edu Kelly Minde, Zone Representative,

kminde@unityhouse.com

Edie Smith, Zone Secretary

Zone 10-(Schuyler, Tompkins, Cortland, Chenango, Broome, Tioga, and Chemung Counties)

If you are in Zone 10 and interested in connecting with a neighboring Zone for educational opportunities or networking please contact one of the officers in the neighboring Zone, who will be happy to assist you.

Membership Committee

Let's give big shout out to the members of Zone 7! The Zone has reorganized and currently has 44 members -they may well become our largest Zone in 2019 – definitely a challenge to all of our Zones! The establishment of a Membership Committee within their Zone, chaired by Rosie DelaCruz, has proven to be a successful effort, and according to Co-Chairs Doris Figueroa and Chinazo Echeyona Johnson, there are lots of educational, mentoring and social events planned for the year. We wish you the best of luck as you grow your Zone!

Welcome to new members:
Zone 3: Tara Sandford-Briggs
Zone 6: Michelle Colbert, Jennifer Giamundo, Jean
Cicotte and Christina Wong.
Zone 7: Rhodora Tajo, Maria Jocelyn Garcia, Daniel
Duperval, Samantha Ramos-White, Ann Dabrell,
Patricia Hanniford, Jason Charles, Susan Mazzella,
Mordecai Erps, Vilena Dementyeva, Rosanna
DiLillo, Carol Kanellopoulos, Tara Smith, HuiHui Li
and Daniel Edukuye

Please remember that renewals are due by April 1st – stay involved and reach out to other ID/DD nurses to join our Association!

Cathy Engel, BSN, RN, CDDN Membership Committee Chairperson

DDNA Update 2/19

The 27th Annual Developmental Disabilities Nurses Association Conference will be held in New Orleans June 8 – 10, 2019 with a Pre-Conference on Friday, June 7, 2019. The Conference will be held at the New Orleans Downtown Marriott at the Convention Center, with a room rate of \$165/ night. Registration information will be available soon – please note that early bird pricing will end on 3/31/19.

Two concurrent sessions will be offered at the Pre-Conference:

Certification Boot Camp: Key Concepts in Certification Preparation

Seizure Update and Management Saturday's sessions will focus on Personal Development for the DD Nurse, as well as presentations related to the Developmental Disabilities Nursing Specialty.

Tracks will be offered on Sunday: the DD Nurse as an Advocate, an Educator and a Practitioner will give participants an opportunity to attend sessions of their particular interest. A track on Neurodevelopmental Syndromes will also be offered.

Barb Bancroft will also be back with a presentation "For the Health of It!" on Monday.

The Certification Exam will be offered at the Conference on Monday, June 10, 2019 at 2:00 p.m. If you have not yet applied to sit for the exam OR your exam eligibility has expired, the deadline for the Certification Exam Application must be received in the DDNA offices by 3/15/19. To learn more and to download the exam application, please visit: https://ddna.org/certification/becoming-certified. If you have been previously approved to sit for the CDDN/DDC exam, and your eligibility period has NOT expired, you must register for the exam by sending your registration form and exam fee to the DDNA offices to be received by 5/01/19. If you are not sure of your application or registration@ddna.org

If you are interested in presenting a poster session at the conference, posters will be accepted in two categories:

Research in Developmental Disabilities Nursing Staff/Client/Family Education Resources or Programs

For more information please visit the DDNA

website: ddna.org

Spotlight on Down Syndrome

Each year approximately 6,000 babies are born with Down syndrome (1 in every 700 babies). Down syndrome occurs when a person has an extra copy of chromosome 21. A person has 23 pairs of chromosomes, 22 chromosomes and an X chromosome are inherited from their mother and 22 chromosomes and an X (if female) or Y chromosome (if male) are inherited from their father. 95% of the cases of Down syndrome are trisomy 21 –the person inherits three - number 21 chromosomes. Translocation accounts for 4% of the cases of Down syndrome and occurs when part of chromosome breaks off and attaches to another chromosome. This maybe familial or de novo (occurring spontaneously). Mosaicism accounts for 1% of the cases of Down syndrome and occurs after the initial cell division. There is a mixture of two types of cells, some have 46, others have 47 chromosomes.

The signs and symptoms of Down syndrome include distinct facial features, almond shaped eyes, epicanthal folds, low muscle tone, low set ears, short necks, simian crease of the palm and developmental delays. Generally developmental milestones are met later than in the typical child. The medical issues associated with Down syndrome are heart, thyroid, gastrointestinal, vision and hearing issues and sleep apnea. Atlantoaxial instability- (AAI) an increased mobility at the first and second cervical vertebrae needs to be assessed for. If present, there needs to be careful positioning during anesthesia and dental procedures and restrictions on contact sport activities. In order to help the child meet their full potential early intervention, OT, PT, Speech therapy should be utilized. A referral to a Down syndrome support group is extremely helpful to the fámilies.

An excellent set of guidelines, "Health Supervision for Children with Down syndrome is accessible at: pediatrics.aapublications.org/content/128/2/393. As people with Down syndrome age, their health care needs change. A free publication entitled "Aging and Down Syndrome: A Health & Wellbeing Guidebook is available through the National Down Syndrome Society.

References: National Down Syndrome Society, National Association for Down Syndrome, CDC-Center for Disease Control, NICHD.NIH.gov, and American Academy of Pediatrics.

Provided by Maureen Gavin BSN RN-BC CDDN

2019 ANNUAL SCHOLARSHIP

Scholarship applications are being accepted through March 31, 2019 Guidelines may be found and printed from the web site. www.nysidddna.org

Each year up to a \$1,000 scholarship is awarded to an LPN or Direct Support Professional who is currently matriculated in an accredited RN program in NYS, is a NYS resident and intends to work as an ID/DD RN upon graduation.

New York State ID/DD Nurses Association, Inc. Membership Application/Renewal Form

New Members - Complete all information. Renewing Members - Complete only name and changes. Check <u>all</u> that apply:

☐ New Member (full membership) ☐ Renewing Member ☐ Associate Member*
Name
□ RN □ LPN □ RN Student □ LPN Student Do you hold CDDN? □ yes □ no
Nurse License Number
Home Address
City, State, ZipCounty
Home Telephone Email
Work Site/Agency Name
Work Address
City, State, ZipCounty
Work Telephone Email
School Attending (associate member only)

SEND ALL MAILINGS TO: HOME WORK

ANNUAL MEMBERSHIP FEE (Membership Year is April 1-March 31):
Full Membership \$45 Associate Membership* \$15

Make check/money order payable to NYS ID/DD Nurses Association, Inc. Mail application and payment to PO Box 32, Hannawa Falls, NY 13647

^{*} Associate members are full time RN or LPN students or inactive (retired or unemployed), and are non-voting members. Associate members are not LPNs or RNs.

SAVE THE DATES!

NYS ID/DD NURSES ASSOCIATION

35th Annual Conference September 16-18, 2019: Monday—Wednesday! Holiday Inn, Saratoga NY

Tentative Topics

Safe Patient Handling – Complying with NYS Requirements
Wound Prevention and Care Strategies for the ID/DD Population
The One Key Strategy to Sustainably Elevate Clinical & Social Determinants of Health for People with IDD
Successfully Hiring and Keeping Good Nurses
Counting Sheep: Identifying Common Causes of Sleep Disorder in Individuals with ID/DD The Depth and Breadth: Understanding the Sexuality Related Needs and Concerns of People with I/DD Borderline Personality Disorder in Intellectually Disabled Persons: A Complex Interaction
A Grounded Theory Study of How Parents Made the Decision About Residential Group Home Placement for Their Adult Child with Intellectual/Development Disabilities

What's up with Survey? Trends in Regulatory Agency Findings

Principles of Documentation in I/DD Nursing: How, Why and What to Document

End of Life Decision Making and MOLST

OPWDD Update 2019