

NYS ID/DD NURSES ASSOCIATION NEWSLETTER

Vol. 26, Number Two

Summer 2019

President's Message



Colleagues:

Summer is finally here! Your Executive Board met May 9 and 10 in Syracuse with fifteen members present. We had great discussion and focus on the good of the individuals we serve, the nursing specialty of ID/DD Nursing, the Association and the nurse membership. The

Strategic Plan has been updated to include use of additional social media to promote ID/DD Nursing, complete the work on the New Nurse Orientation Curriculum for ID/DD Specialty, strategies to prevent nurse burnout by addressing nursing workload, and continue development of new leaders within the Association. Utilizing the strategic planning process to guide the activities of the Association has been viewed as positive by our Exec Board members and keeps us focused on our work at hand. I'm looking forward to sharing our progress this year at the Fall Conference and hope that you will be part of our forward movement.

The Saratoga Springs conference site is always the most popular and we hope to see each of you there. We are trying a Monday—Wednesday format this year to avoid attendees giving up so much of their weekend at home time. Your feedback related to that will be important in determining dates of future conferences.

Darlene Langkau dlangkau@hotmail.com

Membership Committee

Our membership count is currently at 258. Please remember that renewals were due by April 1st – you must be a member by July 15 in order to register at the member rate for conference!

Membership Committee Continued

Welcome to new members:

Zone 1: Dawn Haase, and Anna Lenga

Zone 2: Tiffany Eckler, Jolene Edick, Nancy Lewis, Sandra LaGasse, Katherine Matt, and Kristina Southfield

Zone 4: Morgan Manchester, Mariellen Schuck, and Tracy Wellman.

Zone 5: Margaret Simmurra and Deronica Austin Zone 6: Chelsea Dagradi, Elif Desimone, Deborah Arnone, Amber Distafano, Layla Weston, Laura Musselwhite, Patricia Russell, Diana Tambone, Diane Poulos, Linda Easley, Muriene Reed, and Stuart Lui.

Zone 7: Chinazo Echezona-Johnson, Kaitlin Rupp and Christina Dibella

Zone 8: Amy Patterson and Ariel Corcoran Zone 9 &11: Tiffany Searight, Mary deCocq, Julia Field, and Cafina Wilson.

> Cathy Engel, BSN, RN, CDDN Membership Committee Chairperson

WEBSITE and SOCIAL MEDIA REPORT

We are increasing our social media presence and finding new ways to connect to members. We ask for your participation in growing our platforms. Please utilize the following social media platforms to find out the latest NYS ID/DDNA news, as well as share information and practice concerns.

Twitter https://twitter.com/nysidddna LinkedIn https://twitter.com/dd_nys Facebook NYSidddna Website www.nysidddna.org

The website and Facebook are being managed by Committee Chairperson Trish Potocar (Zone 1). Chinazo Echezona (Zone 7) has joined the committee to lead Twitter and LinkedIn.

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)

The zone met in June in Malone with speaker secured from Neurocrine on the topic of tardive dyskinesia and Ingrezza. There is interest in a summer meeting with the presentation topic TBD. For information contact Trish Potocar tpotocar@slnysarc.org or Karen Jarvis kjarvis@slnysarc.org

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

Zone 2 is meeting on June 28 at Casey's place at 11 am for a lunch and learn on the Dexcom glucose monitoring system. We are planning to also meet at the fall conference. We will keep members updated on which night this will take place.

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

Zone 3-(Hamilton, Fulton, Warren, Washington and Saratoga Counties)

For further information contact Anne Payette at hansona2001@yahoo.com.

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

The March meeting was about Ingrezza, the June meeting was in Oneonta and Sue Prendergast was available by teleconference. The August meeting will be at Springbook. For further information contact Co-Chairpersons Carol Krueger – 607-287-7621 (w) or Lindsay Parker – Lparker@wildwoodprograms.org

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

The spring meeting had a presentation on measles by the Department of Health. The next meeting is in October.

For more information contact Zone Representative Sandra Mellion (914)907-3719 sandramellion@gmail.com

Zone 6-(Nassau and Suffolk Counties)

Please feel free to contact our co-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@qmail.com

Zone 7-(New York, Richmond, King and Queens Counties)

Zone 7 has been meeting monthly to promote involvement. The April meeting was on drug overdoses and attendees were trained on Narcan. The last meeting was June 17.

For further information on future meetings contact co-chairs **Co-Chairpersons**- Doris Figueroa 917-282-7298 or Chinazo Echezona-Johnson <u>CEchezona@sus.org</u>

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

Zone 8 is trying quarterly meetings and will be also having a holiday get together at the end of the year. For further information, contact Co-Chairpersons Jane Dash 716-822-2369 or Janet Boland 716 432 4991 (cell) Janet.Boland@aspirewny.org

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 at Starbridge Inc. 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 May 2019 meeting guest speaker was Claire Louise Herrman RN, BSN; Department of Public Health; Communicable Disease Prevention and Control from Monroe County, who presented on *Summertime in Public Health*; nursing implications, data, info on Lyme Disease, Substance Abuse/Opoid Crisis, Measles outbreak, and outdoor pest issue. Current recommended vaccine schedules were reviewed. A schedule can be obtained at www.cdc.gov/vaccines/schedule

The last 2019 Meeting is scheduled for October 8, 2019, 1-3pm at Starbridge Inc..

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

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.

Proposed Dues Increase

The NYS ID/DD Nurses Association Executive Board has voted to propose a dues increase for the consideration of the membership at the Annual Meeting. The proposal will raise dues to \$50 full membership and \$30 associate. This is a \$5 increase for full members and brings associate dues up to the cost of providing the membership.

Proposed Bylaw Revisions

The Bylaws Committee, composed of Cathy Engel, Trish Potocar, and Avril Marshall, Chairperson, is proposing the following changes in the Bylaws, reviewed and approved by the Executive Board at their spring meeting. The Bylaws will be presented at the September Annual Meeting at the conference for a vote by the full membership.

For the sake of newsletter space, only the Articles/ Sections to be amended are provided below. The notes in italics offer the rationale.

Article I - Name

Section I – the change is to insert NYS – see underlined section below.

This non-political, non-profit organization shall be known as the "Intellectual Disabilities/ Developmental Disabilities Nurses' Association, Inc.," and shall be known by its acronym, "NYS ID/DD Nurses' Association, Inc."

Article III - Membership

Section I - the change is to delete the language requiring dues to go to the treasurer – see strikethrough section below.

 Application for both full and associate membership and payment of dues shall be submitted to the Treasurer annually.

Article IV - The Executive Board

Section I - the change is to add zone secretary as a possible attendee at Exec Board meetings.

A. The Executive Board shall consist of Elected Officers, standing committee chairpersons, zone representatives, zone chairpersons/presidents, zone secretaries, and zone treasurers.

Article V - Elected Officers

Section II - the change is to clean up the language consistent with a previous Bylaws amendment.

An elected officer's term of office shall be for two years and shall commence on the first of the year following election. Maximum tenure shall be six consecutive years in any given office. The term of office of the President and President Elect will be extended to 2 years each starting with the election of 2008 until the first four year commitment has been completed.

Article VI - Elections

- Section I the change is to make the cut off date for membership for voting to be July 1 rather than June. 1 as ballots are usually mailed about August 1. Changes to B. allow electronic transmission of election materials. A new D is added to prohibit Nominating Committee members from nominating themselves. (Just good practice)
- A. 1. Election of the officers of the association shall be by a secured ballot (e.g. mailed, e-mailed, faxed, personal delivery) and shall be submitted prior to the Annual Meeting.
- Only those individuals who are full members on <u>July 1</u>st of the current year are eligible to vote in the election.
- B. 1. At least four weeks prior to the election, the Nominating Committee shall mail <u>send</u> to each registered full member, biographical information regarding candidates for election, and an official ballot.
- a. Candidates for election are responsible for submitting biographical information to the Nominating Committee by <u>July 1st</u> of the year in which they are candidates.
 - b. Such biographical material may be edited by the Nominating Committee to accommodate available space.

Ballots must be received by the Nominating Committee before the "Call to Order" of the Annual Meeting.

Nominating Committee members may not run for office.

Proposed Bylaw Revisions Continued

Section II

A. The Nominating Committee shall determine that secured ballots are received from those individuals who were members on **July 1st** of the current year.

Section III - the change is only to match the language to current practice.

Election of the President Elect shall be every two years. An individual may hold each office (President, President Elect) three (3) times. A special election will be held if the office of President Elect becomes vacant.

Election of the Recording Secretary and President-Elect shall be held on odd numbered years and election of Treasurer and Corresponding Secretary on even numbered years. Terms of office shall be for two years and commence on the first of the year following election. Maximum tenure shall be six (6) consecutive years in each of the offices.

Article VII - Duties of Officers

Section I - the change is to eliminate the requirement for two signatures on checks, but to allow the President to still have signing authority. Has not been done in years.

The President shall:

D. Sign all checks with the Treasurer. <u>Sign</u>
<u>checks in the absence of the</u>
<u>treasurer.</u>

Section V - the changes are to be consistent with current practice and to allow leeway for payments to zones based upon the mechanism of maintaining zone funds. (It is harder and harder for zones to maintain their own checking account).

The Treasurer shall:

- A. Have care and custody of all funds of the Corporation.
- B. Make an annual financial report to the membership including a proposed budget and dues schedule for the coming year.
- C. Sign all checks with the President. <u>In the absence of the treasurer, the President may sign checks.</u>
- D. Return a percentage Allocate a portion of annual dues paid, to zone chairperson/ treasurer for use within each organization zone.

Article VIII - Meetings

Section III - the change is new language added as a new D.

D. <u>Inactivity in a zone for more than one (1)</u> <u>year, defined as no regular meetings, will</u>

result in the zone being declared "inactive" and the following will occur:

The \$15 membership payment allotted to the zone will cease. Funds that are being held for/by the zone will revert to the general treasury.

Should the zone become active again, they will be provided with start-up funds equal to the amount of \$15 membership payment allotted to the zone they would have been paid in the preceding year had the zone been active. The Zone may also apply to the Executive Board for start-up funds in excess of that amount.

Article IX - Standing Committees

Section I - the change is to allow electronic transmission of the biographical information and to eliminate duplicate provisions that are stated elsewhere.

Nominating Committee

C. The committee shall prepare a slate of candidates for election. At least four weeks prior to the election, the committee shall mail <u>send</u> pertinent biographical information regarding nominees, which has been submitted by the candidates in a timely manner, and if necessary, edited by the committee to accommodate available space. An official ballot shall be sent to each individual who is a registered member on August 1st of the current year.

Section III - the change is from acting as an advisor to actually being the chairperson.

Newsletter Committee

A. The Chairperson of this committee shall be appointed by the President and approved by the Executive Board.

The Corresponding Secretary shall act as **chairperson of** this committee.

Article XII - Offices

The change allows the offices to be where ever the executive board determines.

The principal office of the Corporation shall be in Pierrepont, County of St. Lawrence, State of New York with a mailing address of PO Box 32, Hannawa Falls, NY 13647. The Corporation may also have offices at such other places within this state as the board may from time to time determine or the business of the Corporation may require.



Joyce Binder: Memorial Award Application

Awarded to an outstanding NYS ID/DD member who has made a significant contribution to advancing the practice of supporting individuals with ID/DD through the demonstrated attributes of caring/compassion, advocacy, mentoring, leadership, dedication, education/ research.

Name of Nominee/Title:
Experience of Nominee:
Nominee is a member of NYS ID/DD Nurses Association as of Aug. 1, 2019? Yes Unknown
Describe how this nurse has/will change the quality of life and has made a positive impact for the people he/she supports:
Attributes this nominee has demonstrated, in at least 150 words: (May attach a brief typed summary of explanation for the distinguished attributes identified with examples of how the nominee has demonstrated those qualities.)
Nominating Person and Relationship to Nominee:
Contact Information:

Please submit by mail this completed application before 8/15/19 to:

NYS ID/DD Nurses Association

PO BOX 32

Hannawa Falls, NY 13647

CDC Issues New Recommendations for TB Testing

The Centers for Disease Control and Prevention (CDC) has announced a 3 to 10 month shortage of <u>Aplisol</u> (tuberculin purified protein derivative [PPD], diluted). Par Pharmaceuticals, the manufacturer of Aplisol, alerted the CDC that Aplisol 5mL (50 tests) are already in short supply, while the 1mL product (10 tests) is expected to be in shortage by November 2019 or earlier.

The CDC recommends three general approaches to prevent a decrease in TB testing capability because of the expected shortage of APLISOL®.

- Substitute IGRA blood tests for TSTs. Clinicians who use the IGRA blood tests should be aware that the criteria for test interpretation are different from the criteria for interpreting TSTs.
- Substitute TUBERSOL® for APLISOL® for skin testing. In cross-sectional studies, the two skin test products give similar results for most patients.
- Prioritize allocation of TSTs, in consultation with state and local public health authorities. Prioritization might require the deferment of testing some persons. CDC recommends testing only for persons who are at risk of TB. High-risk groups for TB infection include:
 - People who are recent contacts exposed to persons with TB disease;
 - People born in or who frequently travel to countries where TB disease is common;
 - People who currently or used to live in large group settings, such as homeless shelters or correctional facilities;
 - People with weaker immune systems, such as those with certain health conditions or taking certain medications that may alter immunity; and
 - Children, especially those under age 5, if they are in one of the risk groups noted above.

While overall test concordance is high, switching between PPD skin test products or between TSTs and blood tests in serial testing may cause apparent conversions of results from negative to positive or reversions from positive to negative. This may be due to inherent inter-product or intermethod discordance, rather than change in *M. tuberculosis* infection status. Clinicians should assess test results based on the person's likelihood of infection and risk of progression to TB disease, if infected.

In settings with a low likelihood of TB exposure, the deferment of routine serial testing should be considered in consultation with public health and occupational health authorities. Annual TB testing of health care personnel is not recommended unless there is a known exposure or ongoing transmission .

Source: https://emergency.cdc.gov/han/han00420.asp?deliveryName=DM1457

Spotlight on Fragile X syndrome

Fragile X syndrome (FXS) is the most common inherited cause of intellectual disability. It received its name because under a microscope, part of the X chromosome appears "broken" or "fragile." FXS is caused by the expansion of the FMR1, (Fragile X Mental Retardation 1) gene. The Fragile X gene can be passed on in families from one generation to another. Males are more severely affected than females. Physical features of FXS include large ears, low muscle tone, long face and large testicles (at puberty). They also may have learning and intellectual disabilities, ADHD, poor eye contact, anxiety, speech, motor, and language delays. Children with FXS may benefit from early intervention programs, speech and occupational and behavioral therapies.

A fragile X carrier does not show any obvious signs of FXS but has an altered FMR1 gene and can pass it on to future generations. Some carriers of FXS may have high levels of anxiety. Fragile X-associated primary ovarian insufficiency (FXPOI) can be seen in females who have a form of the Fragile X gene called a "premutation." It can cause reduced ovarian function, infertility, and early menopause.

Fragile X-associated tremor/ataxia syndrome (FXTAS) is an adult-onset (over age 50) neurological condition that causes memory issues, tremors, balance and other neurological and psychiatric symptoms in people who are carriers of FXS. Fragile X testing is recommended for anyone who has a family history of FXS, intellectual disability, autism, infertility issues with premature ovarian failure or adult onset ataxia or tremors. The genetics of FXS are very complicated and far reaching, genetic counseling is strongly recommended when someone is a diagnosed with FXS or is a carrier of FXS.

References

Health Supervision for Children with Fragile X Syndrome

Joseph H. Hersh, Robert A. Saul, Committee on Genetics

National Fragile X foundation: Fragile X 101, A guide for the newly-diagnosed and those already living with Fragile X. www.fragilex.org

Submitted: Maureen Gavin RN-BC CDDN

Congratulations to Linda Cultrara for her promotion to the DDRO covering Region 1. She will be covering safe admissions and discharges, hospital placements, and end of life care. We wish you all the best in your new endeavor!

Early Bird Rate Due August 1
Registration Deadline
August 30, 2019

35th Annual Conference Sept. 16-18, 2019 Saratoga Springs, NY

Registration Form

For full conference details go to www.nysidddna.org

Name					 			
Employer								
□ Home Address □ Work Address								
Phone								
Email								
NYS ID/DD Nurses Association Zone If zone not known, give county								
□ RN □ LPN □ NP	□ Other	Please	Please list your choice of sessions for each time block					
Registration Fees Enclo		Monday	Preconference BLS	Yes \$25.00	No			
Must be member of NYS ID/DD Nurses Assoc. by <u>July 15, 2019</u> to qualify for member rate. DDNA membership does not qualify.		Monday	First Timers Orientation	01	O2			
Preconference □ \$25 with conference registration		Monday	Concurrent Sessions	12:45-2:15 M1	1:00-2:15 M2			
Full Conference Registration		Monday	Mini-Sessions	M4 M5	M6 M7			
□ \$290 Member Early Bird (due 8/1)□ \$315 Member (due 8/30)		Tuesday	10:00-11:15 am	T2	T3			
□ \$350 Nonmember Early Bird (due 8/1) □ \$375 Nonmember (due 8/30)		Tuesday	2:15—3:30 pm	T5	T6			
One Day Registration	Day	Wednesday	9:45-11:00 am	W1	W2			
□ \$150 Member Early Bird (due 8/1) □ \$160 Member (due 8/30)	Attending:	Wednesday	1:45-2:45 pm	W4	W5			
□ \$175 Nonmember Early Bird (due 8/1)	□ Tuesday □ Wednesday	Wednesday	"Bonus" Session 3:00—4:00 pm	V	N6			
Conference Meals & Session Selections No refunds will be given for registration cancellations after 12					s after 12:00			

Conference Meals & Session Selections Please select only the meals & sessions you will attend					
Tuesday	Breakfast	□ Yes □ No			
	Lunch	□ Yes	□ No		
Wednesday	Breakfast	□ Yes	□ No		
	Lunch	□ Yes	□ No		
Please check box for □ Vegetarian Meals □ Gluten Free					

No refunds will be given for registration cancellations after 12:00 noon on 9-11-19. Substitutions are allowed.

Hotel rooms are not included in the conference registration. The room rate is \$139 +tax, single or double. Please make reservations with the Holiday Inn Saratoga Springs by August 31. The room block may sell out prior to that date so call early. The group code is IDN.

The hotel direct phone number is (518) 584-4550.

For Purchase Orders, the Federal ID # is 22-2570251

Email: information@nysidddna.org Fax: 315-379-0619

We are sorry but we can not accept telephone registrations. Registration forms paid by PayPal or Purchase Order may be faxed to 315-379-0619. PayPal assesses an additional fee which is added to the registration rate.



NYS ID/DD NURSES ASSOCIATION

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

Tentative Topics

- The One Key Strategy to Sustainably Elevate Clinical & Social Determinants of Health for People with IDD
 - Safe Patient Handling Complying with NYS Requirements
 - 2 Part: Wound Prevention and Care Strategies for the ID/DD Population
 - Successfully Hiring and Keeping Good Nurses
 - Counting Sheep: Identifying Common Causes of Sleep Disorder in Individuals with ID/DD
- The Psychosexual Assessment and Treatment Continuum: Understanding the Socio-sexual Needs and Challenges 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