



# NYS ID/DD NURSES ASSOCIATION NEWSLETTER

Vol. 26, Number Three

Fall 2019

## President's Message



It was so nice to see so many old friends and meet some new friends at the Annual Conference. Congratulations to the Conference Committee on putting together such an awesome variety of topics and such dynamic speakers.

Congratulations also to our newly elected officers --- Mary Jean Keegan as President Elect and Carol Krueger as Recording Secretary. Thank you to them and to the other candidates who volunteered to offer their time and talents to our association.

This year's recipient of the Joyce Binder Award was Joan Nowak from Zone 9 & 11. Joan was not able to be at the conference but was presented her award at a Zone meeting. Congratulations Joan.

The end of my term as your Association President is drawing near. I want to thank all of you for your faith in me to hold this office and your support throughout my term. I have had the pleasure to meet and collaborate with such excellent nurses. I thank all of you for the passion and commitment you show in providing care to our ID/DD individuals. You provide them with the opportunities to live a healthy & inclusive life. I commend you all.

As the holidays are upon us, I hope you all enjoy good health, an abundance of happiness and the love you all deserve.

Darlene Langkau  
[dlangkau@hotmail.com](mailto:dlangkau@hotmail.com)

## WEBSITE and SOCIAL MEDIA REPORT

Twitter <https://twitter.com/nysiddna>

LinkedIn [https://twitter.com/dd\\_nys](https://twitter.com/dd_nys)

Facebook NYSiddna

Website [www.nysiddna.org](http://www.nysiddna.org)

For those of you that would like to sign up for membership or renew it can be done through the website and paypal. This not only is an efficient way to accomplish this process but ends up saving us money in the time and correspondence needed to gather all the information. You can also download an application and pay by check or purchase order if you wish to do that. A new management service will start with the new year and we expect the transition to go smoothly. In the meantime new material can be added by Trish Potocar [tpotocar@slnysarc.org](mailto:tpotocar@slnysarc.org) or Nancy Rutledge [information@nysiddna.org](mailto:information@nysiddna.org). We welcome any suggestions or things you would like to see.

Facebook: **NY State ID/DD Nurses Association**

-If anyone has pictures from the conference send them to Trish or Karen and we could post them. Also send any comments you have. We have 169 likes to the facebook page currently. We add a few more after every conference or event. Let other nurses in your organizations know we exist. Visit the facebook page and do a "like" and the feed will be connected to your personal facebook page. Look for updates on information regarding the Nurses Association and it's membership. If you have news on any member and/or photos please send to [tpotocar@slnysarc.org](mailto:tpotocar@slnysarc.org) or [kjarvis@slnysarc.org](mailto:kjarvis@slnysarc.org).

[tpotocar@slnysarc.org](mailto: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)**

On Nov 1 Zone 1 had a meeting at Lobster House with speaker Jennifer Warren, RPh. She presented on the medication Epidiolex, as well as other current medication concerns. In April of 2020 they have a meeting planned with Dr Fred Wetzel presenting. Details to be announced. Co-Chairpersons: Trish Potocar ([tpotocar@slnysarc.org](mailto:tpotocar@slnysarc.org)) and Martin Gleeson ([Mart.4950@gmail.com](mailto:Mart.4950@gmail.com))

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

It was so nice to see the Zone 2 members who were able to attend conference. We really enjoyed meeting at Cantina Restaurant. If anyone has ideas on what they would like presented at a meeting or would be willing to host a meeting, please contact Amanda Aiello ([aaaiello@archerkimer.org](mailto:aaaiello@archerkimer.org)). We would like to set up all meetings for 2020 ahead of time to get out to all Zone members. Happy fall everyone!

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

Welcome to new co-chairs Sean Casey and Tara Sanford-Briggs. Our next quarterly meeting will be scheduled in late winter with details to be forthcoming. Watch for emails from Tara or Sean.

Anyone interested in participating or who wishes to be added to the zone email list should contact Anne Payette, NP at [hansona2001@yahoo.com](mailto:hansona2001@yahoo.com).

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

Zone 4 continues to be an active group. On June 19<sup>th</sup> we had our quarterly meeting/training hosted by ARC Otsego with a presentation by Susan Prendergast RN, BS Director of Nursing through OPWDD via a video conference on "Happenings in OPWDD." Our August meeting/training was moved to September 26<sup>th</sup> and hosted by Springbrook. We had a pediatric neurologist Dr. Julia Holtmann and the VNS representative – Leighann Karker speak. Our Holiday party/meeting is scheduled for December 5<sup>th</sup> at the Reel Seafood Co. in Albany, NY. We plan to hold our elections for Chair, Secretary and Treasurer. If interested for running for an office within zone 4 – please contact Alyson Ligon – secretary of zone 4.

Submitted by Alyson Ligon, RN – Zone 4 Secretary

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

### **Zone 6-(Nassau and Suffolk Counties)**

On 10-22-19 Zone 6 held its fall meeting at FREE's Skills Unlimited site. The topic "Differentiated Scope of Nursing Practice LPN, RN and AMAP" was presented by the infamous Dr Fred Wetzel. In attendance was about 30 RN's and LPN's which made for an interesting conversation and dialogue. Angelo from Hudson Regional Pharmacy was gracious enough to cater in hot food which was enjoyed by all. Holiday plans are still in the works so keep an eye out for the flyer. Dates for 2020 meetings are currently being discussed. If you have any topics or speakers you would like to see at our meetings, please reach out to Zone Officers.

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

Zone 7 continues to meet monthly in efforts to increase the membership. As of October 2019, the membership is steadily growing. The Zone members met at the September NYSIDDDNA conference at Saratoga Springs and are pictured below.



The Zone continues to host experts in the field of ID/DD specialty. These presenters include physicians, OPWDD experts, IDD/DD nursing leadership and other nursing specialties. Upcoming topics and meeting dates are:

Date	Presenter	Time
December 17	Christmas Party	12pm-2pm
January 20	Corum	1pm-3pm
February 24	Mhh	1pm-3pm
March 23	ChemRx	1pm-3pm

## Zone Reports con't

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

Zone 8 met in September for an Epidiolex training and dinner hosted by Greenwich Biosciences. At that meeting we collected our donations for the basket giveaway for the NYS ID/DDNA conference. Our theme was "Snow Day in Buffalo" and items included a variety of comfort food and drink items, things to do to on a cold blustery day and even some "Blizzard" memorabilia. At the conference, 11 members met and agreed to continue Quarterly meetings the second Wednesday of January, April, July and September. Our next meeting will be January 8<sup>th</sup> for our Holiday get together. Details will follow!

### **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 two to three times a year 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 Stammersky, zone president. The zone officer positions of secretary and president are up this year, and we are seeking any interested in members.

At our October 8<sup>th</sup> meeting, Sue Korpeck MA, RN, from CP Rochester's Augustin Children's Center spoke on severe bleeding, trauma, lacerations, and how to acutely treat until aid arrives.

In a new collaboration, we would like to welcome into our zone the students and nurses completing graduate work at St. John Fisher College Golisano Institute for Developmental Disability Nursing. The Golisano Institute for Developmental Disability Nursing is designed to transform the health care and support of individuals with developmental disabilities.

In October 2018, St. John Fisher College, Tom Golisano, and the Golisano Foundation announced the creation of the Golisano Institute for Developmental Disability (DD) Nursing thanks to a \$5.8 million gift, \$5 million from Tom Golisano and \$800,000 from the Golisano Foundation. The Institute will be fully integrated into the Wegmans School of Nursing and is designed to transform the health care and support of individuals with developmental disabilities. It will be the first

institute of its kind, and will have local, national, and international impact.

Looking forward to an exciting year!!!

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 include you.

## **The World Health Organization (WHO) Named 2020 as International Year of Nurse and Midwife**

*Reprinted from the WHO web site: <https://www.who.int/>*

Nurses and midwives play a vital role in providing health services. These are the people who devote their lives to caring for mothers and children; giving lifesaving immunizations and health advice; looking after older people and generally meeting everyday essential health needs. They are often, the first and only point of care in their communities. Quite simply, the world will only achieve universal health coverage by recognizing the critical role they play and by investing more in the nursing and midwifery workforce.

So WHO has designated 2020, the bicentenary of the birth of the founder of modern nursing, Florence Nightingale, *The Year of the Nurse and the Midwife* (YONM). Working closely with key partners including, the International Confederation of Midwives (ICM), International Council of Nurses (ICN), Nursing Now and the United Nations Population Fund (UNFPA), we will:

- Celebrate the contributions of health workers, with particular focus on nurses and midwives, in improving health globally,
- acknowledge, appreciate and address the challenging conditions nurses and midwives face while providing care where it's needed most and advocate for increased investments in the nursing and midwifery workforce.

## Dues Increase

The NYS ID/DD Nurses Association Membership has voted at the Annual Meeting to increase 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.

## Membership Committee

Total membership currently is 317, with 15 of those new members for 2020-2021. New members since the last newsletter are:

- Zone 1: Tara Relation and Leane Miller
- Zone 2: Marie Broecker, Johnaelyn Waldron, and Laurie McGrath
- Zone 3: Mary McCasky, Joellen Schwab, Rebecca Reed, and Tavia Hoover
- Zone 4: Courtney Bacon, Michele Davis, Sandra Hyatt, Michelle Hoag, Clairice Vergan, Donna Marie Brooks, and Jennifer Pioggia.
- Zone 5: Bethany Latulipe, Kim Mulpeter, Sarah Madureira, and Sharon O'Dowd
- Zone 6: Margaret Somerville, Crystal McIntosh, Donna Guccione, Sandra Espinal, Denise Axelband, Susan Hughes, Kathryn Mandeli, and Cathy Gipson.
- Zone 7: Kelynn Edmond and Pennapa Castro
- Zone 8: Amanda Strianese, Connie Tambacas, and Darlene Mead
- Zone 9: Karen McGovern-Graham
- Zone 11: Rosemary McCullough, Ashley Teeter, and Sara VanCamp
- Zone 12: Donna Mallet—Connecticut.

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

## Conference Days Survey Results

Thank you to the 82 members who responded to the email survey regarding preferred days for the conference. We tabulated the results by counting responses that indicated first or second choice for the range of days. The clear preference was for Monday-Wednesday.

Sun-Tues: 40.2%  
Mon-Wed: 62.2%  
Tues-Thur: 26.8%  
Wed-Fri: 31.7%  
Thur-Sat: 6.1%  
Fri-Sun: 9.8%  
Sat-Mon: 12.2%

In order to verify our results, we also looked at the percent that selected Mon-Wed as their first choice only and those days was the preference at 41.5% compared to 23.2% for Sun-Tues as first choice.

## Spotlight on Newborn Screening

In the United States, newborn screening (NBS) assesses for serious, treatable, asymptomatic but rare conditions that a baby may have at birth. In the 1960's, the first NBS began with testing for phenylketonuria (PKU). Presently, NBS blood testing is recommended for disorders of organic acid metabolism, fatty acid oxidation, amino acid metabolism, lysosomal storage, hemoglobin, adrenal gland and other disorders including hypothyroidism and cystic fibrosis. Each state decides which tests are required based on the laws of the state, cost, funding, frequency of the disorder and the availability of treatment. Currently, all states screen for at least 31 disorders. New York State screens babies for 60 disorders.

Each year, more than 95% of babies (at least 4 million) born in the US undergo NBS. The NBS test is required of all infants unless the parents confirm in writing that they have a religious objection. It is usually performed within 24-36 hours after birth. The screening includes blood, hearing and heart tests. The NBS blood test is usually performed with a bloodspot obtained using a heel-prick. The blood spot card is shipped to a lab for testing. The results are reported as negative, repeat required (inadequate specimen or inconclusive results) or positive. If positive, the results are reported to the pediatrician and the baby is referred to specialty care center. In the US, about 3,000 newborns test positive for one of these severe disorders. With all of these diseases, early diagnosis is the key to effective treatment.

Baby's first test, [babysfirsttest.org](http://babysfirsttest.org), phone # (800) 336-4363 is our nations resource center for NBS information. It provides resources to help families and healthcare providers at the local, state and national levels.

References:  
March of Dimes, [Wadsworth.org](http://Wadsworth.org)  
[Babysfirsttest.org](http://Babysfirsttest.org), [www.nichd.nih.gov](http://www.nichd.nih.gov)

10/21/2019- Maureen Gavin RN-BC CDDN



# New York State ID/DD Nurses Association, Inc. 2020 Membership Application/Renewal Form

New Members - Complete all information. **Renewing Members** - Complete only name and changes.  
**Check all 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 Ad-  
dress \_\_\_\_\_

City, State,  
Zip \_\_\_\_\_ County \_\_\_\_\_

Home Telephone \_\_\_\_\_ Email \_\_\_\_\_

Work Site/Agency Name \_\_\_\_\_

Work Address \_\_\_\_\_

City, State, Zip \_\_\_\_\_ County \_\_\_\_\_

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 \$50   Associate Membership\* \$30**

\* 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.

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

NYS ID/DD Nurses Association  
PO Box 32  
Hannawa Falls, NY 13647



## **SAVE THE DATE!!**

### **Conference 2020**

**Albany Marriott**  
**September 14-16, 2020**

*Please note this is Monday—Wednesday*

The 2020 Conference Planning Committee will determine speakers and develop an agenda early in 2020. Registration rates have not yet been determined but the hotel room rate will be \$129.00 plus tax, single or double. (\$10 less than last year!)

If you are interested in submitting a proposal to be a speaker, please contact us at [information@nysiddna.org](mailto:information@nysiddna.org)