



NYS ID/DD NURSES ASSOCIATION NEWSLETTER

Vol. 28, Number 1

Winter 2021

President's Message



The NYSIDDDNA is committed to providing education opportunities to its members. Despite the pandemic's impact and causing the cancellation of our annual conference, we strive to meet this goal.

On February 2, 2021, the association hosted a round-table event to discuss topics and share information related to COVID-19, staffing, and nursing concerns. The feedback was extremely positive, and we are planning to hold more in the future.

Our first webinar was held on February 9, 2021, for 128 of our members with Dr. Fred Wetzel, Dr. Vincent Siasoco, and Vanessa Woods RN; OPWDD, speaking on the COVID-19 vaccine and educating staff and DSPs. The annual diabetes update which was emailed to all members will remain available through 2021.

During this time, we encourage sharing of information with nurses working in the field, as it will help individuals we serve. We also look forward to the online educational offerings that our conference committee is working on for later 2021.

We know our strength is in the networking of our members; stay safe and healthy.

Edie Smith, NYSIDDDNA President
edie.smith@cayuga-cc.edu

Please use this mailing address when sending mail to NYSIDDDNA:

NYS ID/DD Nursing Association, Box 25832,
Rochester, NY 14625

(Please do not use the former mailing address.)

Conference Planning Update

As we announced in the November newsletter, we are planning to host two or three ½ day web/zoom based conferences this spring. Our first webinar, "COVID-19: What ID/DD Nurses Need to Know," was held on February 9. Thank you to Dr. Fred Wetzel, Dr. Vincent Siasoco, and Vanessa Woods, RN, Director of Nursing for metro DDSO, for their excellent presentation.

The conference planning team is seeking topics of interest for presentations for the remainder of this year. We plan to reach out to the presenters we had aligned for the postponed 2020 conference for platforms to coordinate some exciting opportunities. As always, we welcome any and all suggestions from our DDNA community. Please send your suggestions for topics to me at information@nysiddna.org.

We also look forward to offering more zoom networking meetings this spring. Our first zoom meeting was a success. Having the opportunity to share ideas, ask questions, and hear how colleagues are addressing the topics discussed in their workplaces was helpful.

Linda Cultrara, Conference Committee Chair
Linda.m.cultrara@opwdd.ny.gov
and *Linda Dudman,*
NYSIDDDNA Planning Manager
information@nysiddna.org

NADSP Resources

National Alliance for Direct Support Professionals

For educational resources for DSPs and COVID, please visit: www.nadsp.org

- NADSP: The Facts about Covid-19 Vaccines for DSPs
- NADSP: Your Questions and Our Answers About the COVID-19 Vaccine for DSPs

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.

Membership Committee Update

Currently, the Association has 239 members. Welcome to our new members! Just a reminder that membership renewals are due on April 1st. Please encourage nurses that you know are in the field to join!

Challenges related to how we practice nursing in this new environment continue and the Association is always looking for ways to be a support to our members, most recently hosting a roundtable discussion on areas of interest and a webinar related to COVID-19. We can all learn from each other's experiences. Networking is a significant focus of the Association.

Many thanks to all of our members for ALL that you do every day. Your roles have never been more important to the individuals we support and to our staff. The past year has been filled with trials and tribulations, opportunities to learn and be creative, and has also provided experiences to expand our technological horizons. We hope that you will continue to look to the Association for support as we all continue to navigate our way.

You may renew your membership by visiting the website www.nysidddna.org. We continue to offer an associate membership at a reduced rate for full or part-time RN/LPN student nurses and nurses who are inactive (retired or unemployed).

*Cathy Engel, BSN, RN, CDDN
Membership Committee Chairperson
cengel@intandem.org*

DDNA Update—February 2021

The 2021 DDNA Annual Conference will be virtual this year! The conference will be held May 18-20, 2021. Live and on-demand presentations will be featured, and CE's will be available. More details will be forthcoming on the DDNA website.

DDNA is planning to celebrate the 2022 Conference in San Antonio, Texas. Keep checking the website for more information as it becomes available!

RN's and LPN's who wish to sit for the certification exam may continue to do so through Prometric testing centers. In accordance with the changing local and federal governance and advice from the CDC and WHO surrounding the COVID-19 pandemic, Prometric will be implementing and adhering to global safety guidelines and legislative policies in their testing centers. Select testing centers are open with 50% capacity to allow for 6 ft. of social distancing and require a face mask. If an individual arrives without a

(Continued in next column)

DDNA Update (Continued)

mask, it is considered a "no show" and the individual is not eligible for a refund or free reschedule. Please visit the Prometric home page website to ensure awareness of all COVID-19 response information. Check the DDNA website for more information related to the certification process.

Nurses seeking continuing education to meet their certification requirements have options available to them. There is free courseware available to members on the DDNA website. On-going webinars have also been offered with certificates of attendance provided. DDNA has provided sponsored commercial educational presentations as well as individual presentations and will accept proposals for presentations.

DDNA has three DDNA Nursing Councils, with two of the three Councils open to all DDNA members. They are a great way to become more involved with DD nursing on a national level:

- The **DDNA Education Council** works to identify relevant venues to promote nursing education about health and healthcare among persons with DD; promote knowledge about health and healthcare among persons with DD to other professionals and the community; promote networking and collaboration among DDNA members interested in this work and disseminate examples of what DDNA members do in these endeavors; and contribute to development of DD collegial learning and continuing education for members.
- The **DDNA Research Council** works to identify relevant problems in DD nursing for research through partnership with professional DD nurses; promote networking and collaboration among DD nurse researchers; and disseminate DD nursing research findings within the DD nursing community and the wider health care community to positively affect healthcare practice and policy for people with developmental disabilities.
- The **DDNA Nursing Practice Council** works at the direction of the DDNA Board of Directors to review DD nursing practice concerns, trends, standards and to draft responses/positions statements on behalf of DDNA. Members of this Council must be certified as a DDC or CDDN and via nomination or self-nomination, are appointed by the DDNA Board of Directors. There is now a 3rd edition of the "Practice Standards of Developmental Disability Nursing" and is available for purchase at \$19.95 for DDNA members and \$39.95 for non-members.

NYSIDDDNA is an affiliate of DDNA; however, memberships are separate. For more information, please visit www.ddna.org.

Prepared by Cathy Engel, BSN, RN, CDDN

NYSIDDDNA Scholarship Opportunity

Deadline for Submission: April 15, 2021

Every year, the New York State ID/DD Nurses Association offers a \$1000 scholarship to encourage LPNs and other staff working in the field of intellectual/developmental disabilities to explore or remain in the field of Intellectual/Developmental Disabilities Nursing.

An announcement about this scholarship was sent to nursing schools throughout New York State. Eligible NYSIDDDNA members can apply. If you know potential candidates, please share this information about the scholarship.

An eligible applicant is:

- An LPN or other non-nurse staff member who is currently working or has previously worked in the intellectual/developmental disabilities field, *and*
- Currently matriculated in an accredited basic RN program, *and*
- A New York State Resident, *and*
- Intending to work as an ID/DD RN in New York State upon graduation.

TO APPLY: Submit one PDF or Word document with the following information:

- **Cover letter** introducing yourself and your interest in the intellectual/developmental disabilities field.
- **Your resume** describing your educational and work experiences.
- **An essay** of not more than 500 words explaining your future educational and professional goals.
- **Proof of current matriculation in the RN program.** Matriculation documentation must be a letter or verification on school letterhead from the Nursing Program or from the College Registrar's Office. A college transcript or course listing is not sufficient for proof of matriculation.

The Scholarship winner will be chosen from the eligible applicants by a selection committee of the NYS ID/DD Nurses Association. The scholarship will be awarded in June 2021.

Applications must be received by **Thursday, April 15**. If you have questions, please write to information@nysiddna.org for assistance.

NYSIDDDNA Website

www.nysiddna.org

Since online is our main way of communicating, currently the Association hopes information posted on the website is helpful. Check the website for forms, newsletters, What's New, and resources. Together we can get through this so continue to support the Association.

The membership application is on our website. Payment can be made by check or PayPal. Information about this year's Scholarship and the Joyce Binder Award can be found on the website. I'm sure we have even more heroes in our membership who shine through this past year.

Let us know if there is new material you would like to see posted. New material can be added by Trish Potocar tpotocar@slnysarc.org or Linda Dudman information@nysiddna.org.

*Submitted by Trish Potocar, RN,
Website Chairperson, tpotocar@slnysarc.org*

NYSIDDDNA Social Media

The depreciation of Internet Explorer in favor of Google Chrome or Firefox can make things a little challenging but believe me we are still out there.

If you cannot find it any other way, simply go to our website and click on the "f" on the homepage. It will take you directly to our Facebook page. Visit the Facebook page and do a "like" to have the feed connected to your personal Facebook page. If you have a question for the membership, news on any member and/or photos, please send to tpotocar@slnysarc.org or kjarvis@slnysarc.org.

For our LinkedIn account, contact Tara Sandford-Briggs at tsandford@cwinc.org.

*Submitted by Trish Potocar, RN,
Website Chairperson, tpotocar@slnysarc.org*

For more information about NYSIDDDNA, check:

- **Twitter:** <https://twitter.com/nysiddna>
- **LinkedIn:** <https://www.linkedin.com/in/new-york-state-idd-nurses-association-4618b691/>
- **Facebook:** NYSiddna
- **Website:** www.nysiddna.org
- **Email:** information@nysiddna.org

Zone Reports

ZONE 1: St. Lawrence, Franklin, Clinton and Essex Counties

Zone 1 members I'm sure are all dealing with the changes and daily challenges that COVID brings to us. We are considering investigating have a meeting plus presenter in Zoom mode. Who knew this time last year we would still be in a holding pattern waiting to see when things start to open up! You can contact Trish, Karen, or Marty at:

Trish Potocar, Zone 1 Co-Chairperson
tpotocar@slnysarc.org | 315-353-6618

Karen Jarvis kjarvis@slnysarc.org 315-353-6618
Marty Gleeson mart4950@gmail.com

ZONE 2: Jefferson, Lewis, Oswego, Oneida, Onondaga, Madison and Herkimer

If you are interested in participating in Zone 2, please write to Melissa or Iellan.

Melissa Britton
Zone 2 Acting Chairperson and Secretary
mbritton@liberty-resources.org
and Iellen Rice, Treasurer, irice@elmcrest.org

ZONE 3: Hamilton, Fulton, Washington, Warren, and Saratoga Counties

Zone 3 is actively seeking new members. If you know anyone interested in participating in Zone 3 activities or if you wish to be added to the zone email list, please contact Tara or Sean.

Sean Casey and Tara Sanford-Briggs
Zone 3 Co-Chairpersons
scasey@caparcny.org or tsandford@cwinc.org

ZONE 4: Albany, Montgomery, Schoharie, Schenectady, Otsego, Delaware, Greene, Rensselaer and Columbia

We had great attendance for our first ever Zone 4 virtual training in December hosted by Wildwoods. Dr. Mullen presented "Challenges in Management of Seizures Associated with LGS" – usage of seizure rescue medication Sympazan. At this meeting we elected our two Zone 4 Representatives for the 2021–2023 term. They are Stephanie Singleman and Alyson Ligon. Congratulations to you both!!

We have a great line up for our 2021 virtual quarterly training/meetings, including:

March 25th (12n), hosted by Springbrook. Neurelis Inc., a pharmaceutical company, will be rolling out their new rescue medication, "Valtoco." All NYSIDDDNA members are welcome. An invitation was sent by email to members.

June 2021 (TBA) SDMC training will be provided

by Cynthia Pross on "Challenging Case Studies" and will be hosted by SDMC/JC.

September 2021 (TBA), hosted by ARC Otsego. Tentative training by the new "Community Dental Health Coordinator" in our area.

December 2021—"Holiday Virtual Get-together" Take Care & Be Well!

Carol Krueger, Zone 4 Secretary
kruegerc@springbrookny.org | 607-287-7621

ZONE 5: Sullivan, Ulster, Dutchess, Orange, Putnam, Rockland, and Westchester

Thank you to Zone 5 members who responded to my message asking if you are interested in taking on a leadership role in the zone. We are looking to schedule a Zone 5 zoom meeting. If you have a preference for day/time, please let me know.

Madlyn Vaillancourt, Zone 5 Secretary
rtgomd@optonline.net | 845-825-1305

ZONE 6: Nassau and Suffolk Counties

Hi from Zone 6 and happy winter to all! Not much is happening at this time due to the COVID-19 restrictions and not being able to hold meetings. The board was discussing doing a virtual meeting and are looking into the logistics of that, maybe late March/early April. Annual membership is due April, so we will be sending out the applications to Zone 6 members for renewal. Please everyone, continue to be and remain safe. We hope that soon we can get back to some semblance of normal. Patty, Laura and Pat

Pat Ruckel, Zone 6 Treasurer
pruckel@phpcares.org

ZONE 7: New York, Richmond, King & Queens

Due to the pandemic, Zone 7 has not had in-person or virtual meetings. Thank you to Lynette Bagot, who agreed to become the Co-Treasurer for our zone. Please reach out to me if you have questions.

Asuncion Muyalde, Zone 7 Treasurer
amuyalde@sinergiany.org

ZONE 8: Niagara, Orleans, Genesee, Wyoming, and Erie Counties

Zone 8 has remained in a hold pattern as COVID has taken grip of our region. Our dedicated nurses continue to be the leaders in training, support, and vaccinations. Our various agencies have been "PODS" for the vaccine as well as collaborating with the DOH, local hospitals, and pharmacies. We are nearing 100% compliance with the individuals we serve and well on our way with vaccine #2!

Zone Reports (Continued)

Continued efforts remain to encourage staff and ease vaccine hesitancy. As we watch our rates of active COVID cases slowly decline, we anticipate being able to resume meetings. Our current networking continues behind the scenes with our DDAWNY collaboration and Zoom opportunities.

Linda M. Cultrara., Zone 8 Secretary
Linda.m.cultrara.@opwdd.ny.gov

ZONE 9: Chautauqua, Cattaraugus, Steuben, and Allegany Counties

ZONE 11: Monroe, Wayne, Ontario, Yates, Cayuga, Seneca, and Livingston Counties

As with most of the Zones, we have held online meetings due to the COVID-19 pandemic and restricted guidelines. We last met on October 13, 2020, via ZOOM to review the Orientation Curriculum highlights. Our next meeting will be held later in March/early April, based on the association's online event schedule. In the meantime, we are supporting each other through this trying time.

We are currently looking for zone members who are interested in being an officer; President, Treasurer, or Secretary, as MaryEllen Stambersky and Edie Smith have held the positions for the last 12 years, and the positions are up this year. Anyone interested can contact Edie Smith, Zone Secretary, or Mary Ellen Stambersky, Zone President.

Edie Smith, Zone 9 & 11 Secretary,
Edie.smith@cayuga-cc.edu

ZONE 10: Schuyler, Tompkins, Cortland, Tioga, Chenango, Broome, and Chemung

Zone 10 is not currently active at this time. If you would like to become a zone officer for Zone 10, contact Edie Smith, NYSIDDDNA President at edie.smith@cayuga-cc.edu. Feel free to connect with another zone and join them for educational presentations and networking opportunities.

COVID-19 Resources from ANA

ANA and the American Society of Health-System Pharmacists have created a new FAQ page with answers to frequently asked questions on COVID-19 vaccines.

Go to www.ana.org and click on "Learn more about COVID-19 Vaccination." Click on "Learn More" and then on "Popular Resources" to find COVID-19 Vaccine FAQs, Guiding Principles for RNs, Vaccine Webinar, and more.

Current NYSIDDDNA Address

In January 2020, the NYSIDDDNA mailing address changed. If your membership dues are paid by your agency, please check to be sure the address has been changed in their accounting system. Mail sent to the previous address will no longer be forwarded to the new address beginning in July 2021.

To assure receipt of your membership dues, please see that the address in your system is listed as: NYSIDDDNA, P.O. Box 25832, Rochester, New York 14625.

Please Note: The NYSIDDDNA email address did not change. It is information@nysiddna.org.

Becoming a NYSIDDDNA Member

The new membership year begins on April 1, 2021. Now is a good time to renew your membership for 2021. If you have colleagues who are not currently members, please encourage them to join NYSIDDDNA for 2021. The annual membership fee is \$50.00 (\$51.80 if paid by PayPal).

Benefits of Membership:

- Engage in networking with colleagues at Zone meetings, the Annual Conference, and online.
- Participate in continuing education opportunities at Zone meetings, the Annual Conference, and through virtual webinars to ensure continued competency.
- Receive support from other nurses who have a wide range of expertise and experience.
- Assume leadership roles at the Zone and the state level.
- Learn about the latest advances and updates in the field.

To Become a Member: Use the application in this newsletter or under the "Join NYSIDDDNA" tab on the website. You will also find links to pay by PayPal. You can pay by check if you prefer.

If You Are Paying by PayPal: Please complete the membership application in addition to completing the PayPal registration information.

Once completed, send the membership application to Linda Dudman, NYSIDDDNA Planning Manager, by mail or email. See the return address on this newsletter for the mailing address. Your membership card will be mailed to you. *Have a question?* Email information@nysiddna.org.

From Your President-Elect

Greetings everyone. Spring is just around the corner! I look forward to spring, particularly after this year. It is definitely a very interesting time to be in the President Elect position for this Association. We are going through transitions and changes, some we anticipated and some we could never have foreseen. In early 2020 who could have ever anticipated the arrival COVID & everything that it would deliver to our doorstep.

Agencies weathered shutdowns for individuals' access to the community, to healthcare, to their meaningful life connections, and to their valued activities. We had individuals and staff become ill with COVID. We have had incredible staffing challenges at the same time that individuals required a really high level of care. We lost folks to COVID. The vaccination process has not exactly been the most user friendly either.

Now agencies are facing possible significant cuts to funding. We nurses have grieved the "old normal" opportunities to gather in person for much needed support within our Zones and for our annual conference.

This Association had many difficult decisions to make. Yet again the annual conference has been postponed this fall because of the concerns relative to the increased workload caused by COVID on nursing caseloads and agencies ability to justify or prioritize spending funds on conference attendance.

Anxiety about the future continues. We finally have vaccines, but we are also encountering many with doubt and fear, who refuse to get the vaccine. OPWDD has reached out to our nurses requesting that we support the education of individuals, their families and the DSPs around the safety and efficacy of the COVID vaccines.

Through all of this, we've reimagined ourselves as an Association in terms of how we best support and mentor nurses in the field of IDD. Over the past year we've hosted virtual meetings and on-line educational presentations. We were pleasantly surprised to see larger than anticipated attendance for these events. Nurses brought their questions, participated in discussions, shared their challenges, their solutions, and their best practices during these virtual events.

As we continue to evolve toward a "new normal," we are looking toward a more permanent solution to support this Association's ability to connect virtually with our members plus continue to support the learning opportunity for all nurses

in the IDD field. We also relish some kind of return to in person lectures, the sharing of our stories, and the nourishment that comes with actually being together.

I've always found that nursing in the IDD field is anything but boring. After all these many years, I am constantly learning. This field demands nurses have the skill set to function independently, to adapt quickly, and to become proficient providing services to individuals who have a multitude of medical diagnoses in addition to their intellectual or developmental disability. We must also creatively train many others to provide care for this variety of complex medical issues.

This Association has always been a lifeline for me in the development of these skills. I have learned so much through my exposure to those dedicated nurses who have mentored and guided me throughout the years.

Attending the Zone meetings and our conferences offered me amazing opportunities to connect with nurses and learn together. Volunteering for various Zone and State Board positions provided me the opportunity to learn with and from some of the best among us. Currently there are opportunities for you to volunteer, to connect with nurses, to learn and to grow within the NYSIDDDNA.

For example, every two years we form a committee to review and revise our Standing Rules and Bylaws. These documents define the responsibilities of the officer positions & our overall mission. This happens to be the year! If you are interested in this opportunity, please reach out to me.

We are also in need of a few tech savvy nurses to help inform the decision process around how to position ourselves to permanently provide virtual as well as in person connection as we go forward to provide education and support for nurses. We definitely need to preserve this vital mentoring, which serves to develop strong nurses, capable of facing challenges. If this year has taught us anything, we know the challenges are coming! We might question whether we should view this past year as one full of obstacles or full of opportunities for change or was it a combination of these two factors. How has the past year prepared us for the next steps we need to take?

We want to position ourselves to continually reinvent the best version of our Association, evolving to develop the increased flexibility to manage each new challenge. And we need each of you, your fresh ideas, different talents and varied experiences to help shape our future.

Mary Jean Keegan, President-Elect
mkeegan@wildwoodprograms.org

Alzheimers Update

Information from Medpage Today 2.8.21

Alzheimer's disease (AD) is generally age-related, non-reversible brain disorder that develops over a period of years. It can be confused with normal aging for a while until the changes in personality, behavior and cognitive skills become more apparent. AD is one type of dementia. Alzheimer's is recognized as the 6th leading cause of death in US adults and may be underreported.

Because the risk for Alzheimer's increases with age and people are living longer, numbers of cases are expected to keep rising. It often is not the cause given on a death certificate.

Doctors look for these changes in the brain to diagnose AD:

- Amyloid plaques, fragments of a protein called beta-amyloid peptide mixed with a collection of additional proteins, remnants of neurons, and bits and pieces of other nerve cells.
- Neurofibrillary tangles (NFTs), found inside neurons, are abnormal collections of a protein called tau. This causes neurons to fail to function normally and eventually die.
- A third occurrence is loss of connections between neurons responsible for memory and learning. Unconnected neurons die and, the affected regions begin to atrophy, or shrink. In this final stage of AD, damage is widespread and brain tissue has shrunk.

Warning Signs

- Memory loss that disrupts daily life (forgetting events, repetition of comments)
- Challenges in planning or solving problems that haven't been seen before (can't pay bills, follow directions)
- Once familiar tasks become a problem (cooking, driving)
- Confusion with time or place (lose concept of events scheduled later or tracking of dates)
- Increase in balance issues (falls, dropping things caused by less understanding of visual images and spatial relations)
- Unable to retrieve words in your memory bank for familiar objects and difficulty maintaining a conversation.
- More than the usual misplacing of items and then finding items in unusual places such as washing machine.
- Judgment changes (lose money management skills, hygiene slips)

- Not wanting to attend work or social events that had been enjoyed previously.
- Noticeable changes in mood/personality (person becomes more easily upset plus instances of being fearful or suspicious)

A variant can happen at a younger age but most AD happens after the age of 65 ("late-onset") AD. Late onset has no clear family connection, but clusters may be seen in some families. Current thought cites a gene variation plus lifestyle and environmental factors. A gene called APOE is thought to be a risk factor for AD.

Medications do not stop or cure but can slow the progression of AD. There are four FDA-approved medications for AD symptoms. Their function is to regulate neurotransmitters that transmit messages between neurons. Success is seen if the drugs help individuals with ADL's/verbal skills and lessen behavior/personality issues. The slowing of symptoms can last from a few months to a few years.

The medications are: Donepezil (Aricept), rivastigmine (Exelon), and galantamine (Razadyne) for mild to moderate AD symptoms. Donepezil is approved to treat severe AD. Memantine (Namenda) is for moderate to severe AD symptoms.

For those of us providing care for the ID/DD population noting changes can be even more difficult, but these variations from baseline skills and behaviors can become apparent with daily observation. Often DSP's will start reporting these changes as they spend the most time with the people we serve. As we have found with other things, care issues are not that different from those used for the non-ID/DD individual.

Thank you to Trish Potocar for submitting this article.

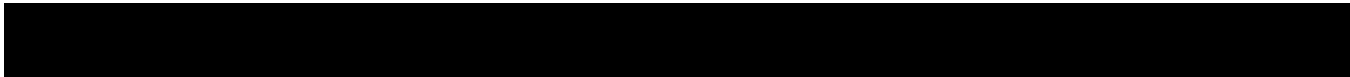
COVID-19 Vaccination Video Series

The Ad Council and the COVID Collaborative have released a video series designed to address health care professionals' questions about COVID-19 vaccination.

The videos include experts from a diverse coalition of leading health care organizations and medical institutions sharing information around COVID-19 vaccine development and safety with their fellow physicians and nurses. The entire video series is available on YouTube.

To access the videos, go to www.youtube.com. Search for "For Physicians & Nurses: Answers to COVID-19 Vaccination Questions for HCPs | Ad Council - YouTube."

NYS ID/DD Nurses Association
PO BOX 25832
Rochester, NY 14625



NYS ID/DD Nurses Association
February 2021

Words of Wisdom for 2021

From Mary Jean Keegan, NYSIDDDNA President-Elect

I read something recently that seems quite pertinent to this point in time. It went something like this:

*If we are to look ahead toward the future through the end of a telescope,
which end will we choose to look through?*

Will we choose the end that makes everything look small and impossibly far away,
OR will we choose the lens that brings those things, which are far away, into perspective,
so that we have a clearer vision of what we are moving toward?

I prefer to think we are looking through that lens that gives us the clear focused perspective.