

President's Message

As you well know, VOR is a national grass roots organization that advocates for the highest quality care for individuals with I/DD and autism and we depend 100% on the generosity of our members to exist.

This year we celebrate the 40th Anniversary of our inception, when some very caring, smart, and determined parents organized and began what was to be VOR's long and continuous journey to fight for the highest quality care, human rights, and for families to have real choices in residential options for individuals with I/DD and autism.

Sadly, we mourn the loss of Polly Spare, one of these very caring, smart, and determined parents, who brought depth and breadth as she served as VOR's second president. More about Polly in the following pages.

As usual, this is the busiest yet most exciting time of the year for VOR. We started our Legislative Initiative on Sunday, May 7 with a briefing of our legislative requests for members of Congress. We have been working with our conference attendees to schedule meetings with congressional staff throughout the month of May, and into June if necessary. Whether speaking with congressional staff in their offices on Capitol Hill, or from your own living room via Zoom, the Legislative Initiative has always offered a great opportunity to engage in advocacy and learn to become a better voice for those who cannot speak for themselves.

This year we are focusing on the critical DSP shortage, as well as several approaches for keeping our family members with intellectual and developmental disabilities and autism safer. And as always, we encourage all of our members to engage with their senators and representatives when they are home in their state offices or making appearances in-district during August. There is no more effective means of illustrating the importance of ICF-level care than to invite your elected officials to visit your loved one in her or his home.

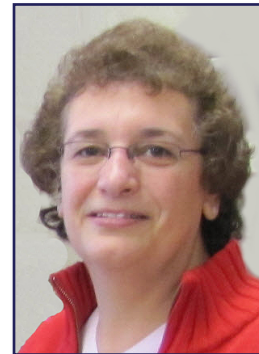
Our Annual Conference is virtual again this year, on Sunday, June 11, so save the date and register online. Registration is free and open to all. You do not need to be a member of VOR to attend. We have a great lineup of speakers again this year, and look forward to hearing from everyone. The Zoom link will be available on our webpage at www.vor.net.

Since 1983, we have depended completely on the generosity of our members and supporters to fund VOR. We had a successful Winter fundraising campaign and yet we find we must appeal to your generosity once again. Because our family members with severe and profound intellectual and developmental disabilities (I/DD), and autism represent only about 5% of the entire population with I/DD and autism we must work very hard to be heard, and even harder to effect policy that will benefit our loved ones. I hope you realize how very, very important your membership and donations are to our very existence. So, I humbly ask again for you to consider a monetary donation to VOR at this time. We are truly grateful for any and **all** donations. One possible method to donate is through a Qualified Charitable Donation directly from a retirement account to VOR which has the potential of substantially reducing the donor's taxable income. As always, we recommend that you contact your tax professional or account administrators before donating in this fashion to ensure that your donation follows the protocols established by the IRS and you receive the full tax benefits.

Most Sincerely,

Joanne St. Amand

Joanne St. Amand,
President, VOR Board of Directors



My name is Casey Henry, I am the mother of Katie Copes.

Katie was born August 27, 2002. At two days old, Katie was diagnosed with Tuberous sclerosis complex (TSC), which is a rare genetic disease that causes non-cancerous (benign) tumors to grow in the brain and several areas of the body, including the spinal cord, nerves, eyes, lungs, heart, kidneys, and skin.

In addition to the numerous medical complications present with TSC, there's also multiple types of behavioral problems associated with this disease including sleep disturbances, attention deficit, hyperactivity, aggressiveness, anxiety, autism, and depression.

Katie, from the age of 2 days old to present, has had multiple complications related to TSC. At just 48 hours of being alive, she was placed on life support due to an Aortic valve blockage by tumors and around 18 months old her seizures began.



As the years passed, the autism, severe intellectual disabilities and the aggression progressed. When Katie reached her early teens, her aggressive behaviors increased, and so did its impact on the rest of our family.

In May of 2018, Katie's heart was stuck in SVT¹ and a heart ablation was performed. Katie underwent major brain surgery April of 2020 in order to remove a giant cell SEGA². The growth of the SEGA was hindering the flow of her spinal fluid. In 2021, Katie had a VNS³ implanted with the hope that it would improve control of her seizures.



Tuberous sclerosis complex drastically changed not only our way of life, but my personal view on the dynamic need of Intermediate Care Facilities, such as Pinecrest. Katie has been a resident of Pinecrest since 2019.

Often, I blamed myself for not being able to handle Katie's episodes alone. As unrealistic as I knew it was for me to feel that way, as I was not and remain unable to physically subdue my daughter safely for either of us. Pinecrest has been an absolute godsend to myself and my daughter. They have given me a way to be a mother to Katie that I would not have had without them. But Pinecrest not only saved me and Katie. It has saved our whole family.

It can be difficult to face the reality of having children with disorders, diseases or disabilities that hinder our ability to be parents. The guilt alone can be crippling. However, by utilizing ICF's, such as Pinecrest, we are able to provide a healthy and happy life for ourselves and our children.

Just this month, I participated in VOR's Legislative Initiative. I was new to this, but I worked with VOR members Mary Kay Cowen and Terry Lafleur, who I know from Pinecrest, and joined in meetings with staff people working in our Louisiana officials' offices in Washington, D.C. One meeting was with Ron Anderson, the Senior Policy Advisor for Sen. Bill Cassidy, who he works with closely. I was both surprised and comforted by hearing Ron Anderson's testimony that his own sister had suffered from TSC. Because of his personal experience, he has great knowledge of the special care my Katie requires. Unfortunately, his sister passed away at the age of 34 in the 90's from this disease. With that said, I pray that he will thoughtfully consider our cry for help, and our gratitude for Pinecrest.

Casey Henry, Mother of Katie Copes

¹ Supraventricular tachycardia (SVT) is a heart condition featuring episodes of an abnormally fast heart rate. The heart will suddenly start racing, then stop racing or slow down abruptly. Episodes can last for seconds, minutes, hours or (in rare cases) days.

² Subependymal giant cell astrocytoma (SEGA) is a tumor that arises in the ventricular system of people with tuberous sclerosis.

³ A Vagus Nerve Stimulator is a device to stimulate the vagus nerve with electrical impulses, which travel to specific areas of the brain, altering brain activity to treat certain conditions. There is one vagus nerve on each side of the body, running from the brain into the chest and stomach.

Do You Have a Story to Tell?

Sharing your story with others helps us understand the diversity of our loved ones, the different choices we have made, the different challenges that face us, and how to stand together to improve the options that are available to us. We need to hear each other. We need to hear your voice. If you would like to share your story, please email us at info@vor.net.



VOR's Legislative Initiative, 2023 Preventing Abuse and Neglect

This has been a challenging year for those of us participating in the initiative. We haven't been able to speak about the most important issue facing people with I/DD and autism or the aging community: the shortage of direct support professionals (DSPs) due primarily to the low wages and lack of benefits they receive. We refer to this as the DSP Crisis, or the Workforce Crisis.

As we all know, the key to solving the DSP Crisis is to provide the women and men who make up this workforce with significantly better wages. The wage paid to DSPs is tied to the federal minimum wage, which has been set at \$7.25 per hour since 2009. Most states make up the difference between the fed wage and their state minimum wage, even exceed it slightly, but don't bring it up to a level where it is easy to attract and retain enough workers to this demanding profession.

As a result, facilities of all types are closing. Individuals with I/DD and autism, members of the aging community, and people with chronic medical conditions are being forced out of their beds, and sent to emergency rooms, psychiatric hospitals, or back to families that are ill-prepared to care for them, physically or emotionally.

Nonetheless, with the House, Senate, and the Executive branch engaged in a budget showdown, and severe cuts to Medicaid on the lips of half of the members of Congress, there is little chance for an increase in DSP wages. In many offices, to begin our conversations with talks of increasing DSP wages is a sure way to close down the entire meeting.

So we have to be careful in how we approach our meetings this year, focusing on what Congress *can do*, and what Congress *might be willing to do*, instead of speaking directly about *what they really need to do*.

Our 2023 Initiative revolves around the issue of keeping vulnerable individuals safe, promoting policies that can lessen the likelihood of incidents of abuse and neglect. And this year, we are not only speaking on behalf of those with the most severe or profound levels of intellectual disabilities and autism who live in larger congregate care facilities. We are speaking for those who live in waiver settings under the Home- and Community-Based Services (HCBS) silo of the Centers for Medicare and Medicaid Services (CMS). We are speaking for the aging community, who also rely on CMS for their care. In fact, we are speaking for everyone within the Medicaid system, whether receiving services or providing care, all the while trying to avoid talking about spending any money on Medicaid. Obviously, this is not an easy task.

Let's be clear. We are not abandoning our support of a full continuum of care, of intermediate care facilities (ICFs), sheltered workshops, or individual and family choice. We never will. That's who we are. But this does give us an opportunity to widen the scope of our advocacy and to live up to our mission statement - to advocate for high quality care and human rights for all people with intellectual and developmental disabilities and autism.

Our goal is to ask members of Congress look at practices that have proved effective in some individual states, and some sensible ideas that have been proposed here and there, and maybe implementing some of those ideas nationally:

1. **Improve systems for reporting incidents of abuse and neglect.** Incidents of abuse and neglect should be reported in a timely manner. Different states have different rules governing the reporting of incidents. According to a 2018 report from the Inspector General of HHS, the Administration of Community Living (ACL) and the HHS Office of Civil Rights, most states have been doing a pretty poor job of reporting these incidents.

We believe that parents and guardians should be notified of *any* incident of abuse or neglect within 24 hours. A written report should be submitted to state authorities within 72 hours, and those authorities, or the parents and guardians of the individual should have the authority to request further investigation, including bringing in state or local law enforcement. There should also be a penalty for persons responsible for the care of vulnerable individuals failing to report incidents of abuse and neglect, whether or not they are directly involved in such incidents.

2. **Promote the use of cameras in LTSS facilities.** Cameras are everywhere. They're in and around banks and bodegas, schools and houses of worship, tollbooths and traffic intersections, front doors, back doors, and wherever nannies might come and go. But they aren't so common in long-term care facilities that house many of our most vulnerable individuals, people with I/DD and autism or the aging population. There are privacy issues, of course. But we aren't talking about bedrooms or bathrooms, but about placing cameras in common areas, at facilities' entrances and exits, and in vans, busses or other vehicles that regularly transport ID/A and aging individuals. People behave better when they know they are on camera, and reviewing footage can exonerate caregivers and providers from liability when there might otherwise be doubt about the circumstances involved in incidents that might occur in these areas.

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This Is What Community Looks Like

By Rita Winkeler

It is often said that individuals who live in ICFs (Intermediate Care Facilities) are isolated, hid away from society, and are not part of the "community". Those of us who have loved ones who live in an ICF know this is a fallacy. The Oxford Dictionary states that a community is "a feeling of fellowship with others, as a result of sharing common attitudes, interests and goals."

Murray Developmental Center in Centralia, Illinois is a community of residents, staff, families, and friends who share the common attitude of safety, care, and fun. Whether the residents are involved in a fun activity such as riding their bikes, planting flowers, or just hanging around with their friends they are involved in what interests them. The staff and families all share the same goal of providing an environment of safety that enables the individuals to reach out, and develop their own goals and interests. This may be through the daily program at Murray Center that works on vocational skills that may someday help those individuals who wish to work in the local area have the skills necessary to do so. It may involve an individual learning to read, so they can learn to play their favorite video game with friends. It may be simple goals, like learning to eat again after surgery, or learning to walk again, but working together as a "community" the resident is able to achieve these goals.

Besides the community of Murray Center, the individuals who call Murray Center home are very involved in the local communities near them. Several have jobs at the local Walmart and McDonalds. They have friendships with their coworkers there, as well as other they meet while working. Several residents follow the local college team, as well as the St. Louis Cardinals, and are seen cheering the team on at their games.



Paul bowls a few frames at the local bowling alley.



Paul enjoys some refreshments after bowling.



Carmen planting flowers for his mom on Mother's Day

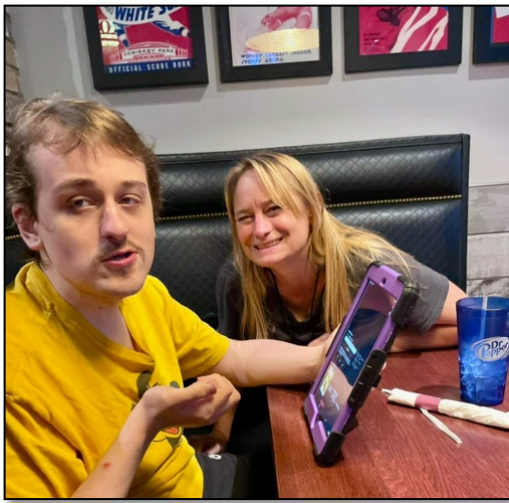
McDonalds. They have friendships with their coworkers there, as well as other they meet while working. Several residents follow the local college team, as well as the St. Louis Cardinals, and are seen cheering the team



Two Murray Center ladies buying flowers at a local garden store.



John meets Fred Bird at a St. Louis Cardinals game.



Max and his mom at a pizza restaurant in Centralia

A popular activity for many of the individuals is Saturday morning shopping....at the local stores, and yard sales, stopping frequently after the shopping trip for lunch at a nearby restaurant. When one of the individuals walk into a store they are frequently welcomed by name. Staff at the stores willingly help those individuals who have special needs, and there is a real attitude of acceptance.



Darryl with his sister Donna at an Ice Cream Social at Murray Center.



Gabby meets a bunny at Buccheit's Pet Store.

The residents have made friendships with others who do not live at Murray Center, and they have spent Christmas, Easter, and other holidays with their friends who live in the towns near them. They attend local proms and dances with these friends, and their friends are also welcomed to Murray Center to share birthdays and special days.

So, to all those who believe that individuals living in ICFs are hidden away the facts prove differently. Explore an ICF, become friends with those who live there, and the truth will come out. ICFs ARE a community, and are part of the larger community in which they reside.



Above: The Murray Center Community attending the Castle Ridge Ballroom Prom in Centralia
Left: Lydia and Tyler dancing / Center: Billy enjoying the music / Right: Renee in her gown and crown

(Continued from P. 3)

We are not asking Congress to enact any laws requiring cameras in LTSS facilities, but that they might consider creating a grant program that would encourage states to promote cameras to help make a safer environment.

3. **Require State Protection and Advocacy agencies (P&As) to actually protect people with I/DD.** That's their job, or at least a big part of it, according to the ACL (<https://acl.gov/programs/pa-programs>), who appropriate tens of millions of dollars to them every year and are supposed to oversee their activities. But people in several states have protested that P&As have been using their resources to try to close down intermediate care facilities (ICFs). They contend that there is a strong "pro-community-living" bias among the people hired to work at the P&As, as well as within the network of state P&As to which they belong, (*the National Disability Rights Network*), their friends at the ACL, and several national I/DD advocacy organizations and self-advocacy groups.

In Illinois, Ohio, and other states, families have borne the costs of hundreds of thousands of dollars in legal fees over several years of court proceedings, trying to oppose class action suits brought on by overzealous P&As that use taxpayer dollars to try to close down Medicaid-certified facilities.

Now some of these states are listening. Ohio passed a law to schedule hearings every two years in the state's General Assembly to allow families to testify about their experiences with the state's P&A, Disability Rights Ohio. During those hearings, a number of families aired serious grievances against DRO, so many that the state is considering taking action, possibly redesignating the P&A entirely. Similar initiatives are being put forward in Illinois.

We feel that every federally funded Protection and Advocacy agency should have Protection as its first priority. That means perform annual, unannounced inspections of all facilities in each state, in-person wellness checks on every individual with I/DD receiving services through Medicaid, and follow-up investigations of reported violations.

We are asking Congress to take a look at the initiatives we see in Ohio and Illinois, and to work to improve the system or redesignate it. P&As should answer to the people they are tasked with protecting. There are no other agencies being funded by the federal government to do this. Let the advocacy groups advocate. We want federally funded oversight agencies to protect vulnerable individuals from abuse and neglect.

And now that we have established that we are serious about keeping safe our loved ones with I/DD and autism and the challenges of aging, it's time to talk about the elephant in the room. People who rely on a stable workforce of reliable, well-trained professionals are not safe if that workforce is falling apart:

Addressing The DSP Crisis

While increasing wages and benefits remain the most important tools for solving the DSP crisis, there are other measures that do not involve budgets or appropriations that Congress can take that will help establish a more stable workforce.

Create a Standard Occupational Classification (SOC) for DSPs within the Office of Management and Budget (OMB) and the Bureau of Labor Statistics. There are 4.5 million DSPs in the United States. They deserve recognition. Having the Federal Government recognize them by creating an SOC would be an important first step in being able to collect data about DSPs, to determine certification and training for DSPs, and for eventually ensuring appropriate wages and benefits for DSPs. Currently, there are companion bills in the Senate and the House that would establish an SOC within OMB. We are asking congressional staff to encourage their offices to cosponsor the

Recognizing the Role of Direct Support Professionals Act (S.1332 /H.R. 2941)

Support a career path and certification programs for DSPs. Being a caregiver is more than a job. It is a profession. A profession within the American Health Care System. Let's treat it as such. As with any other professional service, there should be rewards for experience and length of service. There should be certifications for training in different methodologies and for gaining better understanding of how different intellectual disabilities manifest and change through the course of a person's life. There should be a career path for advancement as a DSP, or into other related health care professions, such as credit towards a nursing degree or an administrative position.

Establish federal standards for DSPs. Background checks are required in all states, but the standards vary greatly. More thorough background checks reduce the potential for instances of abuse and neglect of clients. They also help reinforce the safety of other caregivers, and make them feel assured that their coworkers have everyone's best interests at heart.

We would suggest that all states use the FBI's IAFIS database, and that there be a uniform code for hiring DSPs, so that all people in all states have equal protection against abuse and neglect. Such background checks should be repeated at regular intervals (*every 3 years?*) to ensure that caregivers have not engaged in violent or criminal behaviors since having been hired.

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Increase wages and pay scales equitably for ALL Direct Support Professionals who work with people receiving services through Medicaid. DSP employees should be compensated equitably, regardless of the type of facility in which they serve - not based on the funding stream, or silo, within the CMS system. There are two such silos, one paying for HCBS waiver services, the other for all non-waiver services. Current legislation, notably the Better Care Better Jobs Act and the HCBS Access Act contain provisions to increase wages and training for DSPs who are employed in HCBS programs only. This excludes workers in many private ICFs, nursing homes, skilled nursing facilities, and day programs. By paying some workers and not others, these bills would probably cause a dangerous imbalance in what is already a fragile system.

The bills mentioned above should be amended to reflect this.

Further, since wages for DSPs are currently tied to the federal minimum wage, there are several approaches for updating this policy. VOR supports dialogue that works to develop the policy and legislation that supports employees, employers, patients, and state budgets for DD services.

VOR's 40th Anniversary Annual Meeting

June 11, 2023 - 11:30 am - 5:30 pm (Eastern)

On Zoom

Schedule of Events (All times Eastern)

- 11:30 am Annual Membership Meeting** - This year's agenda will open with a "State of the Organization" speeches from our President, Joanne St. Amand, our Treasurer, Larry Innis, and our Executive Director, Hugo Dwyer, as well as reports from our various committee chairs on their work through the past year.
- 12:30 pm Congressman Glenn Grothman (WI-6)** Representative Grothman has introduced two bills in Congress that would protect sheltered workshops. The **Workplace Choice and Flexibility for Individuals with Disabilities Act** would amend the Rehabilitation Act of 1973 to clarify the definition of competitive integrated employment. The **Restoration of Employment Choice for Adults with Disabilities Act** would amend the Rehabilitation Act of 1973 to ensure workplace choice and opportunity for young adults with disabilities. VOR supports both of these bills.
- 1:30 pm Illinois State Representative Charles (Charlie) Meier (108th District, IL General Assembly)** Rep. Meier has been a strong supporter of the Murray Center, a state-operated ICF in Southern Illinois. He introduced three bills in the IL General Assembly this year to improve the reporting of incidents of abuse and neglect, initiate a demonstration program to determine the effectiveness of cameras in common areas of facilities for people with I/DD, and to require the state to perform unannounced annual inspections of all of its I/DD facilities.
- 2:30 pm Amy S. F. Lutz, PhD.** Dr. Lutz has been a friend to VOR for many years. She is a founding member and vice-president of the National Council on Severe Autism (NCSA). Amy S.F. Lutz's writing about severe autism has been featured on many platforms, including *Psychology Today*, *The Atlantic*, *Slate*, and *Spectrum*. Her first book, *Each Day I Like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children*, was published in 2014. Her second book, a collection of essays called *We Walk: Life with Severe Autism*, was published in 2020. We are anxiously awaiting the arrival of her new book, **Chasing the Intact Mind - How the Severely Autistic and Intellectually Disabled Were Excluded from the Debates That Affect Them Most** to be published in October.
- 3:30 pm Reports from the States** – Every year, we present a forum for our members to submit reports on the State of Their State, to share information about laws, initiatives, and events in their state, both to inspire families in other states to improve their resources and to strategize with others to help preserve choice and a full array of residential and employment options for people with I/DD and autism.
- We encourage all of our members to participate. Please submit your state's report to info@vor.net**
- 5:00 pm Closing Ceremonies** – Swearing in of the new Board of Directors, VOR Voice Award, and other events.

This event is open to all. To register, please go to www.vor.net

Please note: Your membership renewal date is listed at the bottom of the address label on the back page of this issue of The Voice.

Saying Goodbye to a Force for Choice: A Tribute to Polly Spare

By Tamie Hopp

On April 1, 2023, the world said goodbye to Polly Spare.

A leader in the field of intellectual and developmental disabilities, Polly was first and foremost a mother to Sandra, Christopher, Jonathon, and Kathryn. She loved and cared for them with all her heart. Sandra and Christopher, born with severe intellectual disabilities, awakened in her a force that forever changed the landscape of disability policy.

I had the pleasure of having a front row seat, working directly for Polly during her tenure as President of VOR from 1992-1999. VOR needed Polly at that moment in history. Her intellect, charism, leadership, and energy resulted in opportunities to share VOR's perspective in support of residential choice, human rights, and quality care in the media, testimony, courts, and before Congress. Leveraging the work that had been done by founder Marty Pratt, Polly took VOR to new heights. She received awards and earned audiences with key lawmakers and policymakers. These accomplishments enhanced VOR's visibility and credibility and slowed the closure of ICFs/IDD, saving lives and protecting choice.

Polly was also my mentor and friend. I grew as an advocate and professional during my time with VOR, working directly for and with Polly for more than a decade. She taught me and other leaders to lean into our advocacy. She helped families of people with profound disabilities have the courage to use their collective voices, know that they are the experts, and change lives.

The work in support of choice and reason is ongoing today. Advocates continue to visit Capitol Hill and state legislatures, advocating on behalf of their family members. They seek high quality care regardless of setting and, in doing so, speak from the heart as experts. They are doing just as Polly taught, in words and by example.

This is her legacy and we are grateful.



Polly was presented with VOR's VOICE Award at the 2013 Annual Meeting in Washington D.C.

Membership / Contribution Form

Please mail this form to: VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007

Fax to: 877-866-8377 or donate online @ <http://www.vor.net/get-involved>

Thank you for your dues and contributions!

☐ I would like to give a gift membership to:

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☐ MY CONTACT INFORMATION HAS CHANGED

To make a memorial or honorary donation, please
visit our website at:

<http://www.vor.net/get-involved/donate-to-vor>

☐ \$45 per year per individual;

☐ \$200 per year per family organization

☐ \$250 per year per provider / professional org.

☐ I would like to make monthly donations to VOR. Please charge my credit card each month for: \$ _____

☐ I would like to make an additional donation to support VOR. An additional gift is enclosed for:

☐ \$2,500 ☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$50 ☐ Other \$ _____

Make checks payable to VOR, or use your credit card: ☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____ Expires: _____ / _____ CVC (3-Digit Security Code): _____

Signature: _____

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

40th Anniversary logo designed by Starline / Freepik

Spring / Summer, 2023 NL