Wisconsin State Senate
24th Senate District

Serving Wood, Portage, Adams,
Waushara, Monroe, and Jackson

PATRICK TESTIN
STATE SENATOR

DATE: October 12, 2021

RE: **Testimony on Senate Bill 592**

TO: The Senate Health Committee

FROM: Senator Patrick Testin

Thank you fellow members of the Senate Health Committee for accepting my testimony in support of Senate Bill 592.

Representative Dittrich and I introduced this legislation to provide critical resources to parents of a child diagnosed with a congenital condition such as Down syndrome. When a prenatal or postnatal test yields a positive diagnosis for a congenital condition for a baby, parents can face unexpected concern and uncertainty about what the future holds for their child.

Senate Bill 592 requires the Department of Health Services to compile educational materials and contact information for organizations that focus on congenital conditions and provide that material to physicians. We then direct a physician who administers a prenatal or postnatal test that identifies a congenital condition to make sure the parents are provided these resources. Further, this bill directs the DHS to periodically review and update these materials as needed to reflect new research or information. Because the March of Dimes reports one of the most common congenital conditions, Down syndrome, occurs more frequently in our Hispanic and Asian populations, the bill also directs DHS to translate these materials into Spanish and Hmong.

As of January this year, 22 other states have passed similar congenital condition informational legislation. With the passage of this bill, Wisconsin has an opportunity to provide parents welcome context and support to utilize during their child's formative years and beyond. Parents can be reassured with the knowledge that having a child with a congenital condition does not need to be thought of as their child's sole defining characteristic. A positive diagnosis for a congenital condition does not equate to a life without purpose, promise, happiness, or intrinsic value.

Thank you for taking the time to listen to my testimony today, and I respectfully ask that you join me in supporting Senate Bill 592.

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BARBARA DITTRICH

STATE REPRESENTATIVE • 38th ASSEMBLY DISTRICT

October 12, 2021

Senate Committee on Health

RE: Rep. Dittrich Testimony on SB 592 - Relating to: congenital condition educational resources.

Hello, Committee Chair Testin and members of the committee. I appreciate the opportunity to share information with you on a topic that is extremely close to my heart and personal to me, providing information to parents who receive a prenatal diagnosis for their child. As stated in the analysis, this bill requires physicians who administer a prenatal or a postnatal test for a congenital condition and then receive a positive test result to ensure the parent or expectant parent of the child with the positive test result receives certain educational resources on the congenital condition made available by the Department of Health Services.

According to the National Down Syndrome Society, 22 states, both blue and red, have signed such legislation into law. This legislation should provide those building families in Wisconsin great hope, and should equip and empower parents to live a full life with their exceptional child.

Let me walk you through first-hand the story of a couple who would benefit from legislation like this. The mother knew that a certain genetic illness, affecting mostly males, ran in her family of origin. With that in mind, she and her husband decided it was best for them to receive a genetic ultrasound for each pregnancy to determine if she would be delivering a boy. She still remembers having such an ultrasound for the second time and her husband's ashen, gray face when the doctor announced that they would be welcoming a son into the world. The father was afraid, knowing that this son had a 50% chance of being born with this life-altering genetic illness. That mother was me. That father was my husband.

Thankfully, we were well-connected to organizations that could equip us for the son we would be expecting. We were able to prepare for a more gentle delivery, for the safety of that child. We were quickly connected to information that would help us make medical decisions on behalf of our son. And we were connected with another family to mentor us in the early years. That helped us to find our "new normal" and adjust to life with a serious diagnosis more quickly and joyfully than if we had not had that support.

But most expectant or new parents are not as fortunate as my husband and I were. Thus, the need for this legislation. Without such a centralized conduit for information and resources, families can easily become overwhelmed and hopeless. "Dr. Google," as some of my medical professionals have described, can engender fear with inaccurate or incomplete information. Furthermore, fear of the unknown can steal parents' joy, lead to needless despair, and give false expectations of a grim future for their family.

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While medical information can and does definitely keep expectations low for diagnostic outcomes, at least it sets a floor under those in the free-fall of a journey they may not have anticipated. It puts forth a starting line for families to reach higher and make the best decisions for their child. And it lets families know that a life with challenges is still very much a life worth living. There IS hope, and it is incumbent upon us as legislators to make certain our citizens have the opportunity to connect to that hope lest they unnecessarily head down a desperate path.

Let's make certain we join the 22 other states that have adopted this sound legislation. I thank you for your time.

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Testimony in Support of Senate Bill 592: congenital condition educational resources
Senate Committee on Health
By Matt Sande, Director of Legislation

October 12, 2021

Good morning, Chairman Testin and Committee members. My name is Matt Sande and I serve as director of legislation for Pro-Life Wisconsin. Thank you for this opportunity to express our strong support for Senate Bill (SB) 592, legislation requiring physicians who administer prenatal or postnatal tests for congenital conditions provide parents, upon a positive test result, with informative and supportive educational resources made available by the Department of Health Services.

Expectant or new parents can often view a diagnosis of congenital disease or defect almost as if it were death itself. Not a physical death, but a death of hopes and dreams. Visions of a normal childhood vanish in a flash. Studies demonstrate that following a prenatal diagnosis, close to 70% of Down Syndrome babies are aborted in the United States. Parents need to be reassured that there exists detailed information and valuable resources and organizations that can greatly assist them in learning about, caring for, and raising their child.

Senate Bill 592 will go a long way toward encouraging and empowering parents to provide optimal care for their child in such challenging circumstances. Specifically, the legislation requires DHS to provide parents with current, evidence-based information about their child's congenital condition that has been reviewed by medical experts and organizations specializing in that condition. Such information would include the following and more:

- Intellectual and functional development for individuals with a diagnosis of the congenital condition;
- Treatment options for the congenital condition;
- Informational hotlines specific to the congenital condition;
- National and local organizations with a focus on the congenital condition;
- Educational and support programs / Relevant resource centers.

As human beings, we are not just valuable for what we can do, but for who we are. As God's image bearers, we have intrinsic worth, inestimable value, and inviolable dignity. Caring for and loving a child with disabilities allows us to serve someone other than ourselves. It fosters patience, understanding and gratitude for the gifts we have been given. And it allows us to experience the joy of Christ whose life and death was total self-giving, unconditional love for each one of us. We thank Senator Testin for introducing and hearing this much needed legislation. It will save and transform lives. Thank you for your consideration, and I would be happy to answer any questions committee members may have for me.

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Thank you to the members of the Senate Committee on Health, and Chair Testin for your time today. My name is Dr. Richard Bruce, and I am speaking in favor of Senate Bills 592 and 593.

I am a neuroradiologist and clinical informaticist here in Madison. I am also a husband, father, and parent. This is my personal testimony. My wife and I have never before shared our story publicly.

Like many couples, my wife Justine and I anticipated starting a family shortly after we were married. Also like many couples, we found that getting pregnant was not a given. After a year of recurring disappointment, we were ecstatic to find out that we were expecting.

Justine went to her first trimester ultrasound appointment filled with excitement. Initially bubbly and talkative, the ultrasound technologist quickly became silent. She deflected all questions with generic statements about "You will need to speak with your doctor." Terror set in.

A few hours later and still reeling from the ultrasound visit, Justine received a call, and the voice on the other end started with, "When would you like to schedule your genetic counseling appointment?"

Now frantic, she checked her medical record and found the report from the ultrasound. The report impression tersely read, "Cystic hygroma. Major chromosomal abnormality. Refer to genetic counseling." For both of us it felt as though all the oxygen had been sucked out of the atmosphere.

The next week we went together to the genetic counseling appointment. The counselor was pleasant. She went through her information. The numbers she presented were not good. She communicated a minimum of 60% chance of a major chromosomal abnormality. In the absence of a major chromosome abnormality, there was a >20% chance of a major cardiac defect. When asked what were the chances of no defects, she responded in the negative. We were advised that most couples in our situation chose to terminate the pregnancy. We were offered an abortion. We were not offered any information about any other available resources or support groups outside of the genetic counseling and medical services offered.

I can truly say that the bleak information presented to us rocked us to our core. It made us question everything. This was a pregnancy we had been longing for. All of our expectations were suddenly shattered. We felt that all of the joy we were looking forward to had been taken away. When we cried out to Justine's family to share the pain we were experiencing, the response was that we should end this pregnancy and try again. We could not reconcile the thought of destroying the child that we so badly wanted.

We moved our prenatal care to Madison and repeated the ultrasound. The results were unchanged. We were again given tempered but similar projections. We were again offered an abortion. Again we were not directed to any resources beyond the very stark clinical assessment of the various potential genetic abnormalities. Only a single individual within the

spoke to her at that moment through the words of Matthew 25:40, "inasmuch as you did it to one of the least of these My brethren, you did it to Me."

The juxtaposition of Nazi extermination of the mentally handicapped and Becky was not lost on my grandmother. My grandmother became active in the pro-life movement and was the president of Kansas Right to Life in 1972. Yes, that is prior to Roe v. Wade. Kansas had legal abortion before 1973.

I cannot be more proud of my Aunt Becky. She has changed countless lives. She taught me the meaning of unconditional love. You cannot enter the same room as Becky without her introducing herself, "Hi, I'm Becky Myers. What's your name?" She does not hold back her love for others for any reason. She embodies the meaning of humanity far beyond those around her.

Thank you again for your time. I urge your consideration and support for these bills.

WISCONSIN CATHOLIC CONFERENCE

TO: Members, Senate Committee on Health

FROM: Barbara Sella, Associate Director for Respect Life and Social Concerns

DATE: October 12, 2021

RE: SB 592, Congenital Condition Educational Resources

The Wisconsin Catholic Conference (WCC), the public policy voice of the Catholic bishops of Wisconsin, urges you to support Senate Bill 592, which requires that physicians who administer a prenatal or postnatal test for a congenital condition ensure that the parent or expectant parent of the child with a positive test result receives current and evidence-based educational resources on the congenital condition, as made available on the Wisconsin Department of Health Services (DHS) website.

We think physicians will want to share these resources with expectant parents, many of whom will be distressed when they receive an unwanted diagnosis. Parents deserve to know the full scope of their unborn children's condition and should be reassured that medical staff and the larger community are there to support parents as they care for their children or choose to find others to care for them.

We are especially pleased that the bill requires the DHS to list all the supports that exist for specific congenital conditions. Listing these will not just help parents but will also reveal any gaps in resources and supports – gaps that concerned citizens, as well as public and private entities, can work to fill.

SB 592 brings hope and sends the important message that Wisconsin values all human life, no matter what condition it is in. We urge you to support it.

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State of Wisconsin
Department of Health Services
Tony Evers, Governor
Karen E. Timberlake, Interim Secretary

TO: Members of the Senate Committee on Health

FROM: HJ Waukau, Deputy Legislative Director

DATE: October 12, 2021

RE: SB 592, relating to: congenital condition educational resources

The Department would like to take the opportunity to submit written testimony for information only on Senate Bill 592 (SB 592) regarding congenital condition education resources. SB 592 would require the Department to make available on its website, and update appropriately, educational resources for parents or expectant parents of a child who tests positive for a congenital condition. Specified educational resources would also need to be available in English, Spanish, and Hmong translations.

Under s. 253.12, the Wisconsin Birth Defects Registry (Registry) collects information on infants diagnosed with a birth defect. Information provided to the registry is confidential and comprised of birth defects found in children from birth to two years of age, and who are diagnosed or treated in Wisconsin by a physician, pediatric specialty clinic, or hospital. The Registry collects information on 87 specified birth defects and syndromes. Detailed information on which birth defects are reported can be found in DHS 116 Appendix A, a copy which is attached for the Committee's reference. Determinations regarding which conditions are added to or deleted from the Registry are made by unanimous vote of the Council on Birth Defect Prevention and Surveillance. The Council is comprised of medical professionals, a parent/guardian of a child with a birth defect, a representative of a local public health department, and representatives of specified stakeholder groups. Per s. 253.12 (4) (a) the Council is statutorily required to meet four times a year and provide biannual reports to Assembly and Senate Committees on Health, and the Assembly Committee on Children and Families. The Council's most recent report on the Registry and its activities was provided to the Committee on June 18, 2020. The Department is currently able to carry out its statutory requirements related to the Registry, however any additional requirements would necessitate additional financial and staffing resources.

The information provided to the Registry allows regional entities to connect families to support services in their geographic area and provide them with additional information. These activities are accomplished by the Regional Centers for Children and Youth with Special Health Care Needs (CYSHCN). These Centers provide families with information, training, and referrals; including for children with diagnosed birth defects. Along with providing information, the Regional Centers conduct intakes to identify the needs of a family and connects them with the appropriate agencies. The Regional Centers also provide follow-ups to ensure that the needs of the family are being met. There are five Regional Centers in Wisconsin (Northern, Northeast, Southeast, Southern, and Western), and the contact information for each Regional Center is listed on the Department's site: https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm.

The Department is happy to provide any additional information regarding the Registry or the Regional Centers as needed.

Chapter DHS 116

APPENDIX A

Birth Defects and Syndromes for Which Reporting is Mandatory

Achondroplasia	Microphthalmia and Anophthalmia
Ambiguous Genitalia	Microtia/Anotia
Amniotic Bands	Multicystic or Dysplastic Kidney
Anencephaly	Noonan Syndrome
Angelman Syndrome	Obstructive Urinary Tract Defect [not posterior valves; not urethral stenosis/atresia]
Arthrogryposis Multiplex Congenita	Oculoauriculovertebral Association (including Goldenhar Association and Hemifacial Microsomia)
Atrial Septal Defect	Omphalocele
AV Canal/Endocardial Cushion Defect	Osteogenesis Imperfecta
Beckwith–Wiedemann Syndrome	Other Chromosomal Anomaly (not +13, +18, +21, XXY, Turner S., 22q–)
Biliary Atresia	Polycystic Kidney Disease, Autosomal Dominant Form
Bone Dysplasia/Dwarfism, Other (not Achondroplasia)	Polycystic Kidney Disease, Autosomal Recessive Form
Cardiac Arrhythmia (Congenital)	Polycystic Kidney Disease, Uncertain Form
Cataract (Congenital or Early)	Porencephaly
CHARGE Association	Posterior Urethral Valves
Choanal Atresia	Prader–Willi Syndrome
Cleft Lip with or without Cleft Palate	Pyloric Stenosis
Cleft Palate	Rectal/Colonic Atresia/Stenosis
Clubfoot (Congenital)	Reduction Deformity, Arm or Hand
Coarctation of the Aorta	Reduction Deformity, Leg or Foot
Coloboma	Renal Agenesis/Hypoplasia
Craniosynostosis	Robin Malformation Sequence (Pierre Robin Sequence)
Cystic Fibrosis	Scoliosis or Kyphosis/Hemivertebra (Infantile)
De Lange Syndrome (Cornelia De Lange Syndrome)	Small Bowel Atresia/Stenosis
Diaphragmatic Hernia	Smith–Lemli–Opitz Syndrome
Down Syndrome	Sotos Syndrome
Encephalocele	Spina Bifida
Epispadias	Spinal Muscular Atrophy (Infantile)
Exstrophy of the Bladder/Cloaca	Stickler Syndrome
Gastroschisis	Tetralogy of Fallot
Glaucoma (Congenital)	Total Anomalous Pulmonary Venous Return
Hemivertebra	Tracheo–Esophageal Fistula/Esophageal Atresia
Hemophilia	Transposition of the Great Vessels
Hereditary Spherocytosis	Trisomy 13
Hip Dislocation (Congenital)/Developmental Dysplasia of Hip (Congenital)	Trisomy 18
Hirschsprung Disease	Trisomy 21
Holoprosencephaly	Truncus Arteriosus
Hydranencephaly	Turner Syndrome
Hydrocephalus (Congenital or Early)	Urethral Stenosis/Atresia
Hypoplastic Left Heart	Valvular Heart Disease (Congenital)
Hypospadias	VATER Association
Hypothyroidism (Congenital)	Velocardiofacial Syndrome (22q Deletion Syndrome)
Klinefelter Syndrome	Ventricular Septal Defect
Marfan Syndrome	Von Willebrand Disease
Microcephaly (Congenital or Early)	Williams Syndrome

Note: Definitions can be found in the *Birth Defects Encyclopedia: The Comprehensive, Systematic, Illustrated Reference Source for the Diagnosis, Delineation, Etiology, Biodynamics, Occurrence, Prevention, and Treatment of Human Anomalies of Clinical Relevance,* Volumes I and II, Centers for Birth Defects Information Services, Inc. 1990.

To the attention of the State of Wisconsin Legislature (2021-2022)

This is the testimony of Charles Nevsimal in support of 2021 Senate Bill 592 and 593.

Date: Oct 11, 2021

The doctor told her the baby she was carrying in her womb had Down syndrome. He looked at her chart, then spoke again: "I see you have No Termination written here in your chart. Now would be the time to change that decision." Before she was given time to fully process what was happening, the information coming at her so quickly, the doctor spoke again, letting her know she could have it "taken care of right now." By "it," he meant her baby. And by "taken care of," he meant have an abortion.

Thankfully, this woman did not have it "taken care of" that day. Hard as it was for her to reconcile the situation she was in—married, mother of five boys, one of whom stricken with severe cerebral palsy—she knew she wouldn't be able to appropriately care for another child with special needs, not in the way the child deserved. Still, she opted for life.

These events transpired in 2008, the year my wife and I became parents. That woman is our daughter's birth mother, and the child she refused to abort is our daughter. Indeed, our daughter was born with the gift of Down syndrome—which is how we describe it, as a gift. Her name is Gianna Mia Rose, and she turned 13 this past September.

She has a smile that lights up the room and eyes like little pools of galaxy. She loves zebras and dogs and unicorns and Disney princesses. She loves to sing, and has dreams of becoming a YouTube star one day. But she also wants to be a hairstylist—and practices cutting hair on her many Barbie dolls (despite us telling her over and over again that her Barbies' hair won't grow back). She loves Starbucks smoothies (has to be strawberry, though ... and her cup better have a sleeve on it!) She loves swimming and bowling and riding horses and baseball and Friday movie night and praying the rosary, and she insists upon knowing the dinner plans of everyone she encounters throughout her day. She's an exceptional reader, and she writes with fairly decent penmanship. She enjoys learning new things in school. Right now, she's thrilled to be learning about the human heart, given that she had open-heart surgery when she was only five months old.

Her teachers are helping her put together a presentation. I know because I got a notification at work today that my daughter had shared her Google doc with me. She won a gold medal in the 200 meter race at the state Special Olympics in 2019. She loves to chitchat (as she calls it), telling jokes and being silly, especially with her little brother, who she makes laugh hysterically. I could go on and on (and on, trust me), but I won't. I merely wanted to share a glimpse of a life—a life that might otherwise never have existed, had her birth mother taken the advice of her ultrasound specialist. Our daughter brings joy to so many lives. And it's not always easy—sometimes, it's hard as hell. But that's what makes it so special. That's how you know it's something worth fighting for. Something worth defending. Oh, and one more thing: Gianna always makes a point of knowing who's birthday it is, so she can celebrate their big day by sending them a video of her singing Happy Birthday and wishing them the best day ever. The utter serendipity at play here is prophetic!

Our daughter, whose very life was threatened by the possibility of abortion—who could very well have been denied a birthday of her own—has become innately driven to celebrate the birthdays of others. To

celebrate their birth. Because she knows life is a gift. And birthdays are emblematic of every breath of treasured air you've ever taken into your lungs. Our daughter has taught me more about joy and love of life than I could ever deign to teach her.

I encourage you to pass these bills, because no child deserves to be discriminated against—especially while still in the womb. Every unborn child deserves the opportunity to live and teach the world the same joy and love and laughter our daughter has shared with us. Just as every pregnant woman deserves to understand the full potential of joy and love and laughter they bear within their womb.