

Representative • 97<sup>th</sup> Assembly District

June 15, 2021

### Testimony before the Assembly Committee on Education On Assembly Bill 82 / SB 95, relating to: Sudden Cardiac Arrest Awareness

Chairman Thiesfeldt, Vice-Chair Kitchens, members of the Committee, good morning, and thank you for permitting me to testify today on Assembly Bill 82 / Senate Bill 95, relating to sudden cardiac arrest awareness.

In 2019, Waukesha tragically lost one of our own - a student athlete by the name of Kai Lermer. Kai had an undiagnosed heart condition known as 'Wolff Parkinson's White Syndrome.' In a few minutes, Kai's family and friends will share more of Kai's story. I'm grateful for Kai's family, who are choosing to turn a painful tragedy into something positive for other parents and families.

Perhaps the most troubling part of Kai's passing is that he was so young and that his condition was undetected. Knowledge, they say, is power. Kai and his parents did not have the knowledge to ask the right question to the right doctors. We are here today to help fix that gap in knowledge.

Assembly Bill 82 is modeled after Wisconsin's Youth Athlete Concussion Law. It requires the Department of Public Instruction, in consultation with the Wisconsin Interscholastic Athletic Association, and pediatric cardiologists from the Medical College of Wisconsin and the University of Wisconsin-Madison Medical School, to incorporate within the concussion disclosure, information about sudden cardiac arrest. The information provided would include the risks associated with participation in a youth athletic activity after experiencing a sudden cardiac arrest symptom, the potential risks and benefits of electrocardiogram (ECG/EKG) testing, and that a person can request an ECG from their health care provider, at their expense.

This information sheet will be provided to and signed by participants and parents or guardians of those participants 18 years of age or younger.

Thank you again for hearing this bill today. I hope that parents and participants in youth sports will utilize this knowledge, get the simple test, and prevent future tragedies.

I'm happy to answer any questions you have about the bill.



### Testimony before the Assembly Committee on Education

Assembly Bill 82

Tuesday, June 15, 2021

Thank you Chair Thiesfeldt and committee members for taking the time to hear public testimony on Assembly Bill 82. This legislation will provide parents with important information about sudden cardiac arrest as their children compete in high school level athletics.

In April of 2019, Kai Lermer was playing basketball with his friends. Kai felt dizzy, sat down, and then passed out. He was admitted to Children's Hospital, where he was diagnosed with a disease causing erratic heartbeat that led to cardiac arrest. Kai passed away on April 3, 2019. Kai was a Tri-Varsity athlete, competing in football, basketball, and track. Despite completing his annual physicals, Kai never showed signs of a heart condition. After his passing, Kai's family was told that an electrocardiogram (EKG) test could have discovered the heart condition and saved Kai's life.

Assembly Bill 82 requires the Department of Public Instruction to develop an information sheet about sudden cardiac arrest for youth participating in sports. The sheet needs to include information about sudden cardiac arrest symptoms, potential risks and benefits of EKG testing, and how to request an EKG. Assembly Amendment 1 ensures that pediatric cardiologists are consulted during the creation of the information sheet. Assembly Amendment 2 enjoins this information with existing information about concussions. As per current law, in order to participate in sports, this sheet needs to be signed by the youth's parent.

This legislation is modeled after concussion legislation, which also strove to ensure parents are educated about the potential risks of participation in athletics. Unfortunately, since introducing this legislation, I have been contacted by many other parents from Wisconsin with similar stories to the Lermer family. Kai's story is not an outlier, and it's critical that we act to spread public awareness about sudden cardiac arrest in young athletes.

According to the Center for Disease Control, approximately 2,000 young, seemingly healthy people under the age of 25 pas away every year from sudden cardiac arrest. It's my hope Assembly Bill 82 will educate parents and young athletes about the warning signs of sudden cardiac arrest. Not every child will need an EKG, but it's important for parents to be educated when speaking to their child's doctors about participating in sports. I hope to count on your support for Assembly Bill 82, so that we may work together to protect our youth athletes.



# LENA C. TAYLOR

Wisconsin State Senator • 4th District

HERE TO SERVE YOU!

Senator Lena Taylor's Written Testimony Assembly Committee on Education Public Hearing AB 82/SB 95 June 15, 2021

Chairman Theisfeldt, Vice-Chair Kitchens and members of the Assembly Committee on Education thank you for today's public hearing on AB 82, regarding information about sudden cardiac arrest during youth athletic activities.

I've often heard, "when you know better, you do better". AB 82/SB 95 is an opportunity for us to do both. As a result of tragic losses in the field of youth sports, we have come to understand that Sudden Cardiac Arrest (SCA) is the leading cause of death in student athletes. More than 70% of the time, sudden cardiac arrests are preceded by symptoms, which often go unrecognized. In addition, according to medical professionals, 1 in 300 youth have an undetected heart condition that puts them at risk for SCA.

As a result, an increasing number of K-12 schools/districts are turning to sports clearance packets, health history forms, and SCA fact or information sheets, as requirements to participate in school-related sports.

AB 82/SB 95 allows us to make sure more people know the meaning, warning signs/symptoms, and risks associated with SCA. We can better equip parents and students with information regarding the benefit of an electrocardiogram (ECG/EKG). While there is national legislation that goes further to empower coaches to remove students from sporting activities exhibiting believed SCA symptoms and requiring medical clearance to return to play, we know that AB 82/Sb 95 is a good start.

On average, it takes EMS teams up to 12 minutes to arrive to a cardiac emergency. Every minute delayed in attending to a sudden cardiac arrest victim decreases their chance of survival by 10%. We have gotten better at understanding what to do once a SCA situation occurs, we must now do more to help prevent them. I encourage your support of AB 82/SB 95 as one more tool to better the lives and outcomes for Wisconsin youth. Thank you.



WISCONSIN INTERSCHOLASTIC ATHLETIC ASSOCIATION

June 14, 2021

## WIAA Position on Sudden Cardiac Arrest

The Wisconsin Interscholastic Athletic Association supports education and information addressing sudden cardiac arrest; however, the membership believes legislation is not needed with the significant review, education and resources that have been devoted to the topic for many years and the existing resources available.

The considerable amount of information and resource materials exists on the WIAA webpage dedicated exclusively to sudden cardiac arrest at: <u>https://www.wiaawi.org/Health/Sudden-Cardiac-Arrest</u>. The resources present a definition of sudden cardiac arrest, as well as its causes, symptoms and warning signs, screening suggestions. In addition, an emergency action plan is also documented if sudden cardiac arrest occurs.

To further enhance the membership's awareness of sudden cardiac arrest, the WIAA will include information and available online resources with the concussion awareness information that is distributed annually to member schools.

Additional resources linked on the Sudden Cardiac Arrest webpage include:

- <u>NFHS Learn Free Course</u>
- <u>Simons Fund</u>
- Anyone Can Save a Life
- American Heart Association
- <u>August Heart</u>
- <u>Championship Hearts Foundation</u>
- <u>Cypress ECG Project</u>
- Parent Heart Watch
- <u>Emergency Action Plans</u>
- Korey Stringer Institute
- Interaction Task Force

The WIAA website also identifies and links to organizations available for CPR and AED training, as well as how schools can purchase AEDs from manufacturers.

## **UWHealth**

American Family Children's Hospital Contact: Connie Scinize Director, Government Affairs 749 University Row, Suite 240 Madison, WI 53705 608/422-8063 office 608/516-2552 mobile cschulze@uwhealth.org

- **TO:** Rep. Thiesfeldt, Chair Members of the Assembly Committee on Education
- **FR:** Dr. Ellen Wald, Chair, Department of Pediatrics Connie Schulze, Director, Government Affairs
- DT: June 14, 2021

### RE: AB82 - Information about sudden cardiac arrest during youth athletic activities

UW Health American Family Children's Hospital is ranked among the nation's top-50 pediatric cardiology and heart surgery programs by U.S. News and World Report. The program has seen tremendous growth in the last ten years as the health system and UW School of Medicine and Public Health have recruited top pediatric specialists and clinicians to care for very sick children. Furthering the Wisconsin Idea, the program caters to patient families by providing pediatric cardiology clinics at nine locations outside of Madison. From Wausau to Rockford, Illinois, regional clinics save families hours of travel time and expense by allowing their children to be seen close to home by a UW Health pediatric cardiologist. In addition, the program provides excellence in education to medical students, residents and providers already in practice in Wisconsin and surrounding areas.

Given our goal to support and improve the cardiovascular health of children, we read with interest Assembly Bill 82 and we'd like to thank Rep. Allen and Sen. Darling for their leadership in developing and introducing this legislation. Education and awareness play a critical role in preventing injuries and by providing information about sudden cardiac arrest (SCA) to young people involved in athletic activities along with coaches and parents, you hopefully reduce the likelihood of injury and increase the likelihood of seeking medical intervention when necessary.

To that end, please consider amending the legislation to allow pediatric cardiologists from each of Wisconsin's two medical schools, the UW School of Medicine and Public Health and the Medical College of Wisconsin, to serve as advisors to the Department of Public Instruction and Wisconsin Interscholastic Athletic Association. They can use their medical expertise to help shape the information that is shared relative to SCA and further explain the symptoms which can be misinterpreted by those outside the field of medicine.

Thank you very much for your consideration. Please contact us if you have any questions or concerns about the content of this message.



TO:Assembly Committee on EducationFROM:Anoop Singh, MD, Director of Cardiac Electrophysiology, & Kevin Walter, MD, Program Director,<br/>Sports Medicine, Children's WisconsinDATE:Tuesday, June 15, 2021RE:AB 82 – Information about sudden cardiac arrest during youth athletic activities

Chairman Thiesfeldt and members of the Education Committee, thank you for allowing us the opportunity to share our testimony with you today. We are Dr. Anoop Singh, Director of Cardiac Electrophysiology, and Dr. Kevin Walter, Program Director of Sports Medicine – both practicing at Children's Wisconsin.

As the only independent children's hospital in the state, we are 100% dedicated solely to kids' health and well-being. As a nationally ranked hospital, we are proud of our excellent specialty care, including the care provided at the Herma Heart Institute at Children's Wisconsin. We care for patients with congenital heart disease from before birth through adulthood, and we consistently report some of the best surgical outcomes for even the most complex types of heart disease. We are proud to be known as innovators in the field as we continue to challenge the standard of care through new treatments, technologies and follow-up programs that are often adopted by other pediatric hospitals.

Additionally, we are home to Project ADAM, which began in 1999 after the death of Adam Lemel, a Whitefish Bay high school student who collapsed and died while playing basketball. Adam suffered sudden cardiac arrest (SCA) and tragically, no defibrillation or automated external defibrillator (AED) was available. Project ADAM works to provide schools and their staff with cardiac emergency training and AEDs to help prepare schools to protect our children and others in the school community. We have made great strides across Wisconsin and across the country, but we know more can be done to raise awareness and provide improved access to preventive training and resources. Our providers and staff, both inside and outside the hospital settings, are committed to improving outcomes for kids who suffer SCA and to help prevent tragedies like those experienced by both the Lemel and the Lermer families.

Education and awareness are critical to preventing many types of injuries. Helping ensure families have access to factual information and resources regarding SCA is an important and worthwhile effort. The proposed legislation requires the Department of Public Instruction (DPI) to develop an information sheet for parents and caregivers of youth athletes on SCA and electrocardiogram (ECG) testing. We appreciate the amendment to ensure that current pediatric guidance and expertise is reflected in the information sheet through requiring DPI and the Wisconsin Interscholastic Athletic Association (WIAA) to consult with at least two pediatric cardiologists – one from each of the state's medical schools – in developing the information sheet. We believe this requirement will ensure the information sheet reflects evidence-based information that families and caregivers will find valuable.

We acknowledge the Lermer family's personal dedication and commitment to this important issue and thank them for carrying forward their son's legacy to improve the lives of others. We would like to thank Senator Darling and Representative Allen for their work on this important legislation and for their willingness to put forward the amendment to ensure that pediatric providers are able to share their expertise to inform the information sheet. Thank you.

Children's Wisconsin (Children's) serves children and families in every county across the state. We have inpatient hospitals in Milwaukee and the Fox Valley. We care for every part of a child's health, from critical care at one of our hospitals, to routine checkups in our primary care clinics. Children's also provides specialty care, urgent care, emergency care, dental care, school health nurses, foster care and adoption services, family resource centers, child health advocacy, health education, family preservation and support, mental health services, pediatric medical research and the statewide poison hotline.

Children's complies with Federal civil rights laws. We do not discriminate based on race, color, national origin, age, disability or sex. Si no habla inglés, se programarán servicios de idiomas en forma gratuita Llame al (414) 266-7848 (TTY: 414-266-2465). Yog hais tias koj tsis txawj hais lus Askiv, peb yuav teem sij hawm muab kev pab txhais lus pub dawb rau koj. Hu rau (414) 266-7848 (TTY: 414-266-2465).

## Kids deserve the best.



THE MAX SCHEWITZ FOUNDATION One Max, two missions www.HeartSmartEKG.org www.MaxandtheWildThings.com

December 11, 2020

As a cardiologist in the Chicago North Shore region, I also serve as Max Schewitz Foundation's Medical Director. Under this capacity, I personally review EKG's of local high school students and young adults as part of our screening program, HeartSmart EKG, aimed to identify EKG features that place young adults at high risk for sudden cardiac death.

Sudden cardiac arrest in a seemingly healthy young adult is a devastating event to the person, their family and the community. Sudden cardiac arrest is more common in young athletes and thus they deserve a higher level of attention by means of early identification and prevention. Clinical trials over the years has demonstrated that screening has a positive impact on this problem.

With my own personal experience at the Max Schewitz Foundation, I found the screening process extremely inexpensive, and highly effective in diagnosing potential lethal conditions. Since 2007, we have screened 93,879 individuals and diagnosed 2,329 abnormal EKG's, with 924 individuals being referred for further medical evaluation. Many students with abnormal results resulted in procedures or other treatment modalities that hopefully averted unfortunate events.

I fully support the Kai 11 Bill that will increase parents' awareness of risk of sudden cardiac arrest.

Dr. Eli Lavie Medical Director

700 E Park Ave, Ste 105 Libertyville IL 60048 847-648-2206 TAX ID: 20-4855141



Assembly Education Committee:

When I lost my son, Cody, in 2012 to Sudden Cardiac Arrest from an undetected heart issue, I became a member of a club that no one wants to join. I've made it my life's work to help prevent any other families from experiencing this overwhelming and needless loss.

In my home state of Texas we worked six years to get legislation passed and I was proud to see Governor Greg Abbott sign House Bill 76 - Cody's Law in June, 2019. We were the first state to pass a heart screening law, which made it a long, hard road. My hope is that the Lerners will be more successful with your help.

Sudden Cardiac Arrest is the #1 cause of death for student athletes and the #1 cause of death on school property. Research shows heart screening with electrocardiograms (ECG) is the most effective way to detect heart conditions before they cause a tragedy. We believe it is an important addition to the preparticipation physical all athletes must have, as well as all active young people.

This legislation allows parent the option to add ECG screening to the standard school physical. When schools offer lifesaving ECG tests to students they are not only ensuring that our youth have access to the best preventative measures, they are literally saving lives. Everyone should have access to heart screening, no matter where they live, how well they play or how much money their parents earn. With this legislation, it gives parents know the importance and then lets them decide.

#### Our story:

On May 6, 2012, Cody was a few weeks from graduating from Crosby High School near Houston, TX, and looking forward to showing his pig, steer and lamb at the Crosby Fair and Rodeo in June. He was also excited to be headed to Tarleton State University on a football scholarship and working to stay in good physical condition to be prepared for college football practices. Before he died, Cody was talking to me about his goals to play football in a big way in college and beyond. Cody told me, "Go big or go home, Dad." After Cody died, our family turned Cody's motto into a screening effort to prevent other tragedies. It has been a BIG effort in a BIG state - eight years after Cody died, more than 40% of all Texas schools now offer heart screening. and Texas <u>House Bill 76</u> - Cody's Law gives parents in every school district the right to choose heart screening for their child. The Cody Stephens Foundation partners with the largest to the smallest schools, in the big cities and rural communities.

It is my greatest hope to see heart screening legislation in every state, and I am hopeful that Wisconsin will help lead the way with the Kai 11 Bill. Kai's family needs your vote.

Go Big or Go Home,

Scott Stephens, Co-Founder and President Cody Stephens Memorial Foundation



2929 Gettysburg Road Suite 8 Camp Hill, PA 17011 717.695.1917 www.peytonwalker.org EIN# 46-4655102

Assembly Education Committee:

#### Re: Supporting Kai 11 Bill LRB0651

Dear Representative's,

I am writing today to encourage you to support the Kai 11 Bill LRB0651 (AB 82).

Here in Pennsylvania, we successfully passed "Peyton's Law" last July 2020. Peyton's Law was modeled after Cody's Law in Texas – and we became only the second state in the US to pass legislation aimed at preventing sudden cardiac arrest in youth due to detectable and treatable heart conditions.

Peyton's Law passed <u>unanimously</u> in the PA Senate and the PA House – then was reconsidered in both chambers after minor revisions were made. In total, Peyton's Law received over 600 bipartisan votes in favor of the legislation – and not one single vote of opposition. This is remarkable, considering the contentious political landscape we are currently living in. It is a true testament to the purpose and benefit of the law – and I feel confident that **Kai 11 Bill LRB0651** can achieve the same impactful success.

We worked tirelessly for just under 11 months to get this legislation passed.....because we lost our 19-year old daughter to Sudden Cardiac Arrest and have met many families who have faced similar tragedies. Every one of those families wishes they had known to have their children's hearts checked. Please help to ensure that not one more child is tragically lost to a detectable and treatable heart condition.

Our Foundation has provided free heart screenings for over 3,500 teens over the past few years. Remarkably, we have identified about 2% of kids with potentially serious issues that could lead to sudden death. Several students have gone on to receive surgical corrections due to findings from our heart screening events. Their families had no idea their child had a potentially life-threatening heart condition – because the child had never received an electrocardiogram or in-depth heart screening.

In addition, we have flagged an additional 6% of kids with other heart issues or health issues that required further testing or additional follow-up care. These statistics demonstrate the effectiveness of a screening program. Simply stated – heart screenings save lives.

I urge you to shepherd this lifesaving legislation through the legislative process. We were blessed to have an incredible leader in Senator Mike Regan here in PA who guided our bill through the entire process and was able to fast-track it to becoming law.

If we can be a resource to you or your staff as you work on this important legislation, do not hesitate to reach out. We could use more legislative champions across the US – the tide is beginning to swell. My hope is that Wisconsin will become the third state in the country to get this legislation passed.

The beat goes on..... Sincerely,

Julie Walker

Executive Director & Peyton's Mom julie@peytonwalker.org



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Honorable Scott Allen 97th Assembly District 8 West - PO Box 8952 Madison, WI 53708-8952

**RE:** Preventing Sudden Cardiac Arrest/Death in Youth

Dear Representative Allen,

On behalf of Parent Heart Watch (PHW), the national voice solely dedicated to protecting youth from Sudden Cardiac Arrest and preventable Sudden Cardiac Death, I want to extend our enthusiastic support for Kai 11 bill.

Sudden Cardiac Arrest (SCA) has emerged as a recurring cause of death among people under age 25. According to the American Heart Association, SCA affects between 7,000 to 16,000 youth per year. Studies show that 1 in 300 youth has an undetected heart condition. Many children and their parents are unaware they have a potentially fatal heart abnormality until it is too late. In fact, 72% of those who suffered a SCA were reported to experience prior symptoms, but did not recognize them as life threatening.

Youth participating in sports are particularly susceptible, given SCA is the #1 killer of student athletes. The National Center for Catastrophic Sport Injury Research cites that more athletes die from sudden cardiac arrest than from any other sport-related trauma.

The Kai 11 bill will make significant strides in preventing such tragedies by empowering youth, parents/guardians and school staff with education about the warning signs and risk factors associated with sudden cardiac arrest and about the critical steps in the cardiac chain of survival that can make the difference between life and death.

Parent Heart Watch leads and empowers others by sharing information, educating and advocating for change. For more information, please visit www.parentheartwatch.org.

The time is now to protect and save young lives from the perils of sudden cardiac arrest by passing Kai 11 bill.

Sincerely,

Hartes J. y- Juduson

Martha Lopez-Anderson Executive Director

cc: Kai Lermer Memorial Fund



### **Sudden Cardiac Arrest Statistics & Citations**

Sudden Cardiac Arrest (SCA) is the leading cause of death in the U.S. The American Heart Association quotes more than 356,000 out-of-hospital cardiac arrests annually; 347,422 adults and 7,037 children under age 18 (2016/17/18/19). This equates to one youth stricken, nearly every hour, every day, each year. However, it is clear that the AHA reports are not updated annually (given the same number reported for four consecutive years) and information the AHA publishes is often contradictory so a true count remains elusive.

## Out-Of-Hospital Cardiac Arrest in Youth Under Age 18

American Heart Association (AHA) Heart Disease & Stroke Statistics Reports and News



III OHCA in youth not reported. Estimates as high as 14,500 based on 19.7/100,000

AHA News quoted this study in 2018: Alexis A. Topjian, Vinay M. Nadkami and Robert A. Berg, Current Opinion in Critical Care 2009, 15:203–208

As Parent Heart Watch campaign gains momentum, OCHA in youth shows decline

Same number reported for four years in a row, suggesting OHCA in youth is once again not being counted

But what most parents don't know is that:

- SCA is the #1 killer of student athletes<sup>1</sup>
- SCA contributes to the #2 medical cause of death under 25<sup>2</sup>
- SCA is the leading cause of death on school campuses<sup>3</sup>
- 1 in 300 youth have an undetected heart condition that puts them at risk for sudden cardiac arrest<sup>4</sup>

<sup>1</sup>Journal of Athletic Training 2017;52(4):000-000 Harmon et al DOI: 10.1161/CirculatoinAHA.115.015431 <sup>2</sup> <u>https://www.cdc.gov/injury/wisqars/pdf/10lcid all deaths by age group 2010- a.pdf</u> <sup>3</sup> <u>https://www.asumag.com/safety-security/fire-life-safety/article/20850611/shocking-statistics</u>

Prevalence of Cardiovascular Disorders at Risk for SCD

Study	Population	Prevalence	
AHA (2007)	Competitive athletes age 12-35 (US)	0.3%	1 in 333
Fuller (1997)	5,617 high school athletes (US)	D.4%	1 in 250
Corrado (2006)	42,386 athletes age 12-35 (Italy)	0.2%	1 in 500
Wilson (2008)	2,720 athletes & children age 10-17 (UK)	0.3%	1 in 333
Bessem (2009)	428 athletes age 12-35 (Netherlands)	0.7%	1 in 143
Hevia (2009)	1,220 amateur athletes (Spain)	0.15%	1 in 625
Baggish (2010)	530 college athletes (US)	0.6%	1 in 167
Harmon (2015)	47,137 athletes (meta-analysis)	0.3%	1 in 333
Drezner (2016)	S,258 NCAA Div I, II, III athletes (US)	0.25%	1 in 400

<sup>1</sup> in 300 kids have a condition that can cause SCD

A variety of research and data validates the critical need for primary and secondary prevention programs and outreach campaigns that Parent Heart Watch initiates.

- An abstract from the 2014 IOC World Conference on Prevention of Injury & Illness in Sport warned that SCA rates in U.S. high schools are at least 50% greater than reported by media. <u>http://bjsm.bmj.com/content/48/7/605.1.abstract</u>
- The National Center for Catastrophic Sport Injury Research stated that more athletes die from a cardiac arrest than from incurring injuries while playing sports. https://nccsir.unc.edu/files/2013/10/NCCSIR-33rd-Annual-All-Sport-Report-1982 2015.pdf

• Sudden cardiac arrest is one of medicine's most catastrophic and little-understood events. <u>http://www.wsj.com/articles/clues-to-a-familys-heart-disease-1461618257</u>

Conviction that SCA has become of paramount concern for young hearts is further evidenced by a
collaboration between the National Institute for Health and the Centers for Disease Control and
Prevention to create a Sudden Death in the Young Registry to more fully measure the impact this
syndrome is having.

http://www.nih.gov/news-events/news-releases/nih-cdc-launch-registry-sudden-death-young

Yet, of the leading causes of youth death (accidents, suicide, homicide, cancer and heart conditions), SCA is arguably the only one that can be *prevented* through primary and secondary prevention strategies. <u>https://www.cdc.gov/injury/wisgars/pdf/leading\_causes\_of\_death\_by\_age\_group\_2015-a.pdf</u>

A second, more general issue relates to the broader perspective of cardiac arrest as a public health burden. Much of the emphasis in this report, as well as in the Institute of Medicine (IOM) report on the status of cardiac arrest in the US, focused on the response to an impending or actual cardiac arrest. A much larger epidemiological problem is the prediction and prevention of cardiac arrest. A larger cumulative benefit to society would be achieved by *both* reducing the number of cardiac arrests and achieving better outcomes from those that do occur **"We now need a parallel effort to develop a roadmap for improving prediction and prevention of OHCA**."

Myerburg, Journal of the American College of Cardiology dx.doi.org/10.1016/j.jacc.2016.03.611

#### Warning Signs & Risk Factors

SCA is not a heart attack – it's an electrical or structural problem that causes a fatal arrhythmia – a deadly heartbeat. The underlying condition is something you're born with (often inherited) and/or can develop as young hearts grow. The first symptom of SCA is often death, either because the warning signs of an underlying heart condition were not recognized or symptoms were not present.

An American Board of Family Medicine study noted that 72% of students who suffered from SCA were reported by their parents to have at least one symptom before the event—they just didn't recognize it as life threatening.

http://www.medscape.com/viewarticle/767325

The standard approach to youth checkups is a non-cardio focused physical exam/history that misses 90% of youth at risk for SCA.

Maron et al "Autopsy Study of Athletes with SCD (JAMA276:199-204;1996)

We've now known for several decades that *the early recognition of prodromal symptoms could be crucial in the prevention of sudden death* if patients reported warning signs/symptoms to their practitioners, and if practitioners, in turn, had adequate training to respond effectively<sup>1</sup>. Sadly, fewer than half of people who die from SCD and who experienced symptoms before their death sought medical attention for those symptoms.<sup>3</sup> The American Academy of Pediatrics also acknowledged this in their 2012 policy statement on Pediatric Sudden Cardiac Arrest – too often the signals about being at risk for SCA are missed – both by patients and by medical personnel. What's more, in up to 60% of SCDs preceded by symptoms, a cardiac diagnosis was not considered. So, a major factor in the prevention of SCA and SCD in youth is educating patients, parents, and medical practitioners about what signs we need to watch for.<sup>2</sup>

<sup>1</sup> Drory Y, Turetz Y, Hiss Y, et al. Sudden unexpected death in persons less than 40 years of age. Am J Cardiol. 1991;68(13):1388-1392. <sup>2</sup> Drezner JA, Fudge J, Harmon KG, Berger S, Campbell RM, Vetter VL. Warning symptoms and family history in children and young adults with sudden cardiac arrest. J Am Board Fam Med. 2012;25(4):408-415.

Wisten A, Messner T. Symptoms preceding sudden cardiac death in the young are common but often misinterpreted. Scand Cardiovasc J. 2005;39(3):143-149.

<sup>3</sup>Warning Symptoms Are Associated With Survival From Sudden Cardiac Arrest, Ann Intern Med. 2016 Jan 5; 164(1): 23–29 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5624713/

Strong consideration should be given to making the robust cardiac risk assessment available to all students versus just athletes.

Maron BJ, Friedman RA, Kligfield P, et al. Assessment of the 12-lead ECG as a screening test for detection of cardiovascular disease in healthy general populations of young people (12-25 Years of Age): a scientific statement from the American Heart Association and the American College of Cardiology. Circulation. 2014;130(15):1303-1334.

Most early cardiovascular events occur in families with a positive family history of cardiovascular disease. In fact, up to 49% of SCA victims had a significant family history. Eliciting comprehensive and current family history is critical in SCA prevention, which includes inventorying second-degree relatives, including aunts, uncles, cousins and grandparents. Sadly, only 15% of medical practitioners update family histories annually.

- (17) Acheson, L. S., Wiesner, G. L., Zyzanski, S. J., Goodwin, M. A., & Stange, K. C. (2000). Family history-taking in community family practice: implications for genetic screening. Genet Med, 2(3), 180-185. doi:10.109700125817-200005000-00004
- Kahn, J. S., & Weseley, A. J. (2008). When the third degree is necessary: do pediatricians obtain enough information to detect patients at risk for HCM? Pediatr Cardiol, 29(3), 589-596. doi:10.1007/s00246-007-9155-2
- Kluger, C. Z., Morrison, J. A., & Daniels, S. R. (1991). Preventive practices for adult cardiovascular disease in children. J Fam Pract, 33(1), 65-72.
- Williams, R. R., Hunt, S. C., Heiss, G., Province, M. A., Bensen, J. T., Higgins, M., . . . Hopkins, P. N. (2001). Usefulness of cardiovascular family history data for population-based preventive medicine and medical research (the Health Family Tree Study and the NHLBI Family Heart Study). Am J Cardiol, 87(2), 129-135. doi:10.1016/s0002-9149(00)01303-5

Many researchers have concluded that history and physical exam alone are inadequate to detect the conditions that can lead to SCD. In a recent 2019 study, for instance, among 3,620 athletes screened with the addition of the ECG, the AHA/PPE protocols flagged 7/16 kids (43.8%) who ultimately were diagnosed with an SCD-related condition, whereas, the ECG flagged 15/16 (93.8%). So, we know for sure that the PPE or the AHA protocols will miss a good portion (some argue they will miss nearly all) of youth who have an underlying abnormality. Studies also show that the majority of practitioners are largely unaware of national screening guidelines, including recommended use of either the PPE or AHA protocols even as a baseline of preventative care.

- Williams EA, Pelto HF, Toresdahl BG, et al. Performance of the American Heart Association (AHA) 14-Point Evaluation Versus Electrocardiography for the Cardiovascular Screening of High School Athletes: A Prospective Study. J Am Heart Assoc. 2019;8(14):e012235.
- The Preparticipation Physical Evaluation: An Analysis of Clinical Practice, Nicolas L. Madsen, MD, MPH, \* Jonathan A. Drezner, MD, † and Jack C. Salerno, MD (Clin J Sport Med 2014;24:142–149)

Fainting is the #1 sign of a potential heart condition. It's critically important for medical practitioners to recognize exertional syncope and to immediately refer these patients to a pediatric cardiologist.

Sudden Cardiac Death: A Pediatrician's Role, DOI: 10.1542/pir.2018-0241 Pediatrics in Review 2019;40;456 Benjamin H. Hammond, Kenneth G. Zahka and Peter F. Aziz <u>https://pedsinreview.aappublications.org/content/40/9/456</u>

#### **Preventative Youth Heart Screenings**

• In Italy, screenings for high school athletes has led to a 90% reduction in sudden cardiac deaths. J Am Coll Cardiol. 2008 52(24) doi:10.1016/j.jacc.2008.06.053

• With respect to criticism that ECG screening is cost-prohibitive, a U.S. based study by Stanford University of Medicine projected the cost of screening in this country at about \$88 per student athlete and calculated two lives would be saved per 1,000 teens screened, concluding that screening is worth it.

https://med.stanford.edu/news/all-news/2010/03/ecg-testing-of-young-athletes-cost-effective-in-preventing-deaths-study-shows.html

• ECGs are the most effective tool to identify youth and student athletes at risk for sudden cardiac arrest with the lowest false positive rate.

Canadian Journal of Cardiology dx.doi.org/10.1016/j.cjca.2016.06.007; Drezner et al Am J Cardiol 2016; 118:754-759; Drezner et al BJSM 10.1136/bjsports 2016 096606; Journal of Athletic Training 2013;48(4):546-553 doi: 10.4085/1062-6050-48.4.12

- A further 2019 study not only confirms ECG superiority, but underscores that standard history and physical using the AHA-14-point evaluation to determine cardiac risk will miss the majority of athletes with relevant conditions.
- 1. The AHA 14-point evaluation performs poorly compared to ECG for cardiovascular screening of high school athletes.
- 2. The AHA 14-point evaluation produces a high number of false-positive results with a poor sensitivity and low positive predictive value.
- 3. ECG outperforms the AHA 14-point by all measures of statistical performance when interpreted by experienced clinicians.
- 4. Cardiovascular screening using only the AHA 14-point evaluation will miss the majority of athletes with conditions at risk of sudden cardiac death.
- 5. Recommendation for the routine use of the AHA 14-point evaluation, or similar history-based questionnaires, as the principal tool for pre-participation cardiovascular screening of young athletes should be re-evaluated. <u>https://www.ahajournals.org/doi/full/10.1161/JAHA.119.012235</u>

The American Heart Association's panel recommends a standard 14-point screening for young people that includes asking about fainting, chest pain or excessive shortness of breath or fatigue during exercise; premature death or disability due to heart disease or known cardiac conditions involving the heart muscle or heart rhythm in family members; and also includes listening for heart murmurs and checking for other signs that indicate heart or blood vessel disease. **The panel isn't opposed to including ECGs in screening populations if quality control can be assured.** 

https://newsarchive.heart.org/ecgs-wont-save-more-young-people-experts-say/

#### CPR, AEDs and Cardiac Emergency Response Plans

About 91% of SCA victims die because there was a delay in emergency response. Every minute's delay decreases the chance of survival by 10%. <u>http://www.sca-aware.org/about-sca</u>

An estimated 2% of Americans a year get CPR training—an alarming statistic, given one quarter of Americans say they've been in a situation when someone needed CPR. https://www.usnews.com/news/health-news/articles/2019-12-24/prepared-bystanders-save-lives-when-cardiac-arrest-strikes https://www.ishn.com/articles/101451-cpr-gets-simplified http://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=21723

9 in 10 cardiac arrest victims who receive a shock from an AED in the first minute live. 51% of employees don't know where their workplace AED is located.

https://cpr.heart.org/-/media/cpr-files/training-programs/aed-implementation/aed-statistics-infographic-english-ucm\_501517.pdf?la=en

According to the National EMS Information System, it takes an average of 6 minutes (urban/suburban) and 13 minutes (rural areas) for first responders to arrive.

Mell et al, 2017, Emergency Medical Service Response Times in Rural, Suburban and Urban Areas. JAMA Surgery, 152(10), 983-

Every minute delayed in treating an SCA victim decreases survival by 10%. A University of Washington study found that when CPR and an AED are used immediately, the survival rate jumps to 89% when an AED was used by a bystander—so the availability of AEDs is literally a life-saving initiative.

https://www.sciencedaily.com/releases/2018/02/180226085812.htm https://newsroom.uw.edu/postscript/aed-benefit-clear-athletes-sudden-cardiac-arrest

School systems across the United States should have a clear and concise district-wide cardiac emergency response plan that meets laws, standards and safety practices, according to an American Heart Association (AHA) policy statement. This policy statement notes that the goal of a cardiac emergency response plan is to increase the chance of survival after sudden cardiac arrest and decrease the incidence of sudden cardiac death. <u>http://cpr.heart.org/idc/groups/heart-public/@wcm/@ecc/documents/downloadable/ucm\_487599.pdf</u>

- Teach children as young as 6 & 7 to get help for OCHA victim and call 911
- Start teaching CPR as young as 9, recognizing quality chest compressions are more likely at age 13

• Research shown that age 11-12 can properly apply AED within 90 seconds after receiving verbal instructions Advocating for Life Support Training of Children, Parents, Caregivers, School Personnel and the Public: A Technical Report from the AAP, Susan M. Fuchs, MD, FAAP, COMMITTEE ON PEDIATRIC EMERGENCY MEDICINE

### Survival After Exercise-Related SCA in Young Athletes Related to Rapid Resuscitation

• PAD programs should be universal in schools and sporting venues to increase survival

#### AAP Finds AED Use in Children Lacking and Cites Education Campaign as Critical

• Study of 1,398 youth <18 found children age 12+ were 1.4x more likely to have AED used before EMS arrive

- Overall AED applied only 385 cases
- Most events occurred secondary to cardiac etiology



### What is Sudden Cardiac Arrest?

Sudden Cardiac Arrest (SCA) is a life-threatening emergency that occurs when the heart suddenly stops beating. It strikes people of all ages who may seem to be healthy, even children and teens.

When SCA happens, the person collapses and doesn't respond or breathe normally. They may gasp or shake as if having a seizure.

SCA leads to death in minutes if the person does not get help right away. Survival depends on people nearby calling 911. starting CPR<sup>1</sup>, and using an AED<sup>2</sup> as soon as possible.

### **CALL**·PUSH·SHOCK



<sup>2</sup> CPR: Cardiopulmonary resuscitation is when you push hard and fast on the center of chest to make the heart pump; compressions may be given with or without rescue breaths.

<sup>2</sup> AED: Automated external defibrillator is a device that analyzes the heart and if it detects a problem may deliver a shock to restart the heart's normal rhythm.







## Why do heart conditions that put youth at risk go undetected?

- Standard history and physical evaluation misses up to 90% of youth at risk
- An EKG can detect 2/3 of heart conditions that can lead to SCA
- Often youth don't report or recognize symptoms of a potential heart condition
- Parents/Guardians assume youth are okay and just "check the box" on medical forms without asking their child about symptoms
- Youth experiencing symptoms regularly don't recognize these as potentially life-threatening—it's normal to them

### What is an electrocardiogram?

An electrocardiogram (also known as an EKG or ECG) is a quick, painless and noninvasive test that measures and records a moment in time of the heart's electrical activity through small electrode patches attached to the skin of your chest, arms and legs by a technician.

## Why add an EKG to the pre-participation physical evaluation?

Adding an EKG to the pre-participation physical evaluation (PPE) will identify most heart conditions that can lead to SCA and prevent disabilities and sudden death in youth.

- An EKG can be ordered by your physician for screening for heart disease or for a variety of symptoms or a family history of heart disease and will generally be paid for by insurance, ICD 10-CM Code Z03.89.
- EKGs should be read by a medical practitioner proficient in the age group being screened, utilizing current International Criteria for ECG Interpretation in Athletes.
- Like any screening test, if the EKG is abnormal, additional testing and consultation should be done before a diagnosis is made.
- One screening using EKG does not clear the student-athlete for life.
- EKGs should be performed at regular intervals combined with cardiac risk assessment for new symptoms or relevant family history.



#### How common is Sudden Cardiac Arrest?

- SCA affects more than 356,000 people each year in the U.S., including over 7,000 youth under age 18.
- SCA is the #1 killer of student athletes and the leading cause of death on school campuses.
- One in 300 youth has an undetected heart condition that puts them at risk.

## What are the warning signs and symptoms?

- Fainting or seizure, especially during or right after exercise
- Fainting repeatedly or with excitement or startle
- Chest pain or discomfort with exercise
- Racing heart, palpitations or irregular heartbeat
- Dizziness or lightheadedness
- Excessive, unexpected fatigue during or after exercise
- Excessive shortness of breath during exercise

## Why does family history matter?

It is important to gather your family history (parents. siblings, grandparents. aunts, uncles, cousins) and share it with your medical provider as some conditions are inherited:

- any family member with heart disease; even if the condition was treated and remedied
- unexplained fainting or seizures
- unexplained sudden death of a family member under the age of 50

## What are the risks of practicing or playing after experiencing any warning sign or symptom?

By continuing to practice or play without seeking medical attention you risk suffering sudden cardiac arrest, which without immediate action by people nearby could result in death or brain damage. Survival rates are under 10%.

## What if student-athlete is diagnosed with a heart condition that puts him/her at risk for SCA?

- Your medical provider will inform you of the recommended treatment plan, which could include taking medication, making lifestyle modifications to reduce risk (which sometimes means refraining from competitive sports), surgery to correct the issue, or implantable devices that monitor or treat your heart rhythm.
- You will need clearance in writing from a licensed medical practitioner according to the Wisconsin Interscholastic Athletic Association bylaws or state laws.
- It's important to share the student-athlete's treatment plan with school administration, athletic trainers, coaches or any other leaders. As youth caregivers, they must be aware so they can help monitor your child's condition.

## What are some of the causes of Sudden Cardiac Arrest?

- Congenital (runs in families) disease
- Acquired disease (Kawasaki and others)
- Viral heart infection (myocarditis)
- Heart conditions that result from abnormal heart structure or functions
- An abnormality in the electrical system of the heart
- An impact to the chest directly over the heart, also known as commotio cordis
- Drugs (recreational or prescribed) or stimulants that affect the electrical system of the heart, such as performance enhancing or high-caffeine energy drinks or supplements and diet pills



Waukesha North High School 2222 Michigan Avenue Waukesha, WI 53188-3173 262-970-3500 www.waukeshanorth.org

> Principals Office 262-970-3505 Assistant Principals Office 262-970-3518 Student Services 262-970-3531 Athletics 262-970-3519 Attendance 262-970-3516 FAX 262-970-3520 Waukesha School District <u>www.waukesha.k12.wi.us</u>

> > June 11, 2021

To: Wisconsin Assembly Education Committee

Subject: Kai11 Bill (AB 82)

As the Principal of Waukesha North, the High School Mr. Kai Lermer attended for three years and in spirit his senior year, I wanted to share how his tragic passing impacted our entire learning community. I will never forget where I was the afternoon I received the news that Kai collapsed while playing basketball at a neighborhood park with many of his fellow classmates. For the next few days, I prayed for Kai, his parents, and his sister. I also prayed for his classmates and teammates as I knew they first-hand witnessed what ended up being Kai's last breath. I feared how his passing would impact not only Kai's family, but also the mental health of his peers.

Even after an entire community rallied around Kai, unfortunately God had different plans for Kai. As a mother myself, I still struggle comprehending what good could come out of the death of a child and in the case of Kai, the Kai 11 Bill is one answer I can find some peace in. Kai's parents, Mike and Patty Lermer are two of the strongest individuals I have ever had the privilege of meeting. They are both deeply committed to saving the lives of other children by educating teens and families by bringing awareness to the risk of Sudden Cardiac Arrest. Through their work, families learn that EKG testing can help save lives and prevent Sudden Cardiac Arrest from devasting another family by taking the live of another child at way too young of an age!

In the summer of 2020, the Kai Lermer Foundation started their efforts by generously provided Kai's classmates with EKG testing for a small fee. The EKG testing was an invaluable assessment that provided families with confidential information about the health of their child's heart and even identified the heart abnormalities several students unknowingly were living with their entire life, which then allowed for proactive measures to be taken in order to prevent the tragic passing of another child. This was just the start of the work of the Kai Lermer Foundation.



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Principals Office 262-970-3505 Assistant Principals Office 262-970-3518 Student Services 262-970-3531 Athletics 262-970-3519 Attendance 262-970-3516 FAX 262-970-3520 Waukesha School District <u>www.waukesha.k12.wi.us</u>

The Kai 11 Bill would extend awareness of Sudden Cardiac Arrest beyond Waukesha County and would further educate families throughout the entire state of Wisconsin. No parent or school community should ever have to go through the pain of losing a child when there are proactive measures can be taken to detect heart abnormalities. I kindly ask you to consider the tremendous impact the Kai 11 Bill could have on millions of children throughout the state. Please feel free to contact me at any time with any further questions you may have at <u>khiggins@waukesha.k12.wi.us</u> or (262) 970-3510.

Sincerely,

Kristin L.

Kristin L. Higgins

Principal

Waukesha North High School

Dear WI Assembly,

I had known Kai since he was 3 years old. He was best friends with my son Tanner for many years. He was at my house so much for play dates and sleepovers, it was like he was one of my boys. I had seen him grow up to be a smart, athletic, and popular teenager all to be taken away in a moment. When Kai passed away, it was one of the most horrendous days of our lives. We were shocked, angry, and sick with grief over losing such a wonderful friend. He was someone special to our entire family, and he will never be forgotten. You would never have known Kai had a heart defect. He was always healthy, active, and ready for anything. To think just having an EKG done, could have prevented such a loss of a great kid. He was only 16 years old and taken way too soon. You hear about other teenagers collapsing during sports, on the news, the internet, or by word of mouth quite frequently. And it always sounds so horrible and shocking. But when it's someone you know and love, it is ten times worse, and it deeply affects soo many of us. If EKG's would be done during physicals, think of all the young lives that could be saved. Kai could have been saved! Please pass the Kai11 Bill to prevent this tragedy from ever happening again. We miss you and love you always Kai.

Sincerely, Lisa Janotta

#### Logan Tomasello Story:

My beloved son, Logan, died in his sister's arms while away at college from Sudden Cardiac Arrest. He was a college freshman and loving life and his new found adult independence. Logan was a psychology major at UW Milwaukee. He played hockey and the piano, he was his sister's best friend and people were drawn to him because of his sense of humor, outlook on life, compassion and wisdom. He loved it when I hung out with him and his friends, something a lot of teenagers don't appeal to. We were a tight knit family and my son was my world. He was a bright light, and there is a huge hole in my life and of those who knew and loved him.

Logan had an EKG when he was 14 years old due to heart palpitations but the EKG was "normal". He never had another one. I can't help but wish he would have had an EKG yearly as part of his sport physicals or even as part of his college physical.

Please help make "Kai's Law" a reality. Please help save another family from the gripping grief and despair of losing a son or daughter to Sudden Cardiac Arrest by passing this law.

Sincerely,

Monica Tomasello

Hello

My name is Mariette Lermer – I'm Kai's stepmom. It's hard to put on paper who Kai was without becoming emotional. I met him when he was 9 years old, a smart, funny, and very intuitive young man. One day, his dad was away on a business trip and I had to drive him to school. We had 1 hour before class started so we went to a diner to have some breakfast. He sat across from me, quiet at first but broke the ice by asking me questions about my job. He asked about my role as Buyer, what I did every day at work and if I liked my job. I answered his questions and then he said, "hmm, interesting". That was Kai – he always had a way to make you feel at ease. He's life was cut short and we are just left to imagine how great of man he could have been.

We all feel sad when we hear of news of a parent losing a child but to experience it; it's a hard kick in the gut that knocks the breath out of you and a stab that leaves a gaping hole in your heart forever.

There is not a day since Kai passed that my husband did not think of Kai – things they did together; fishing, watching sports and goofing around. Sadly, these fond memories are all that he has of him.

Today is an important day, not just for my family but for all Wisconsin families. We are asking for your support to make sure no other families will ever ask **"What if we had just known?"**. Please vote Yes to pass the Kai 11 Bill.

Thank you.

Arrowhead Union High School Football Matt Harris - Head Football Coach 262.422.8778 <u>matt@epochathletics.com</u> <u>www.arrowheadfootball.com</u>

Wisconsin Legislators:

My name is Matthew Harris. I am the current Head Football Coach at Hartland Arrowhead High School. I was Kai's Head Track & Field Coach and also his Head Football Coach at Waukesha North High School at the time of his passing. I am writing this letter because I am in full support of AB82 (Kai 11 Bill).

As a coach you never prepare to lose. You most definitely never prepare to lose an athlete. I have no words to describe the feelings we all had during these tough times. All I can tell you is that I wish it upon no family, parents, teams or coaches again. This bill will be a great step forward to accomplishing just that to ensure no head coach has to stand in front of a team during times like this.

Kai was an amazing person that is deeply missed by everyone he knew.! Losing Kai was the hardest thing as a coach I have ever gone through. Words will never describe the loss and hurt our community felt grieving through this tragedy. Waiting and hoping this would all pass and Kai would be back on the Football field in the fall. Try and imagine a track team of 100 kids sitting in a gym silent as they hope to hear positive news. Then imagine myself as their leader having to deliver the devastating news. Pass this bill in hopes that we save just one life.

So many people think this cannot happen to them. We all sit in our own world and feel protected from tragedies like this and pass over stories because of that "can't happen to me" feeling. I urge you to not do that with this. This is a no brainer. We need to move fast because every day that passes and every physical that happens it could be the one life we save.

In Conclusion, I am 100% in favor of AB82 (Kai 11 Bill). I look forward to this bill passing and everyone feeling a sense of accomplishment. I also look forward to the lives that will be saved for all the years to come. We will not stop this fight! Kai will be a hero in Wisconsin forever!

Sincerely,

## Matt Harris

Matt Harris

Wisconsin Representative's:

I want to implore you to sponsor the Kai 11 Bill - an important and necessary piece of legislation to help children, families & communities avoid the same tragedy ours has endured!

Undergoing a very simple screening as part of a required physical exam (particularly important for student-athletes) to help diagnose a deadly condition just makes sense-why wouldn't we?! Kai Lermer (lovingly referred to since his passing simply as #11) was a sweet young man with a bright future. He was a wonderful, loving son and brother; a goof-ball, hard-working, loval teammate; and a great student to-boot. Kai was the picture of happiness and health. Kai ate healthier than most of his teenage friends, he worked-out, participated in multiple sports and just loved being active. So. imagine the surprise and extreme heartache of his buddies who were with him as he collapsed after Kai took a break from their basketball game at a park over spring break his junior year of high school (March 2019)! Those boys are still grappling with a guilt - feeling they should have done something else or noticed something earlier to have saved their friend's life. (No one imagines they will attend a healthy 16-year old's funeral!) I could go on & on about the way this unexpected loss affected so many - his parents and family; the teenagers at the park when he collapsed; his coaches and teammates; his teachers and fellow students; his friends and their families... The point of this is that it could have SO easily been avoided had an ECG/EKG been a part of routine screening/examining! We cannot sit by and just allow things to go on and always. We have to react to this great loss to make things better/safer for future student athletes.

I thank you, my family thanks you, Kai's family thanks you, and our Waukesha Northstar community thanks you for your service and taking the time to review and consider the Kai 11 Bill.

Regards, Megan Ramspott 3935 Oakmont Trl. Waukesha, WI 53188 262-349-9635 Wisconsin Education Committee Members:

Good morning. I am Melissa Stark. Kai was my nephew. Kai was an intelligent, athletic, kind, funny young man with a very bright future ahead of him. My favorite memories of Kai were when he was with his cousins, my daughters, Alanna and Kyla, and his sister Kiana. He never failed to tease them all but in the end, he always made them laugh. Kai's death has impacted our family tremendously. We won't have any holidays, birthdays, graduations or family time ever again with Kai. No new memories will be made. My daughters will not have their cousin and I won't have my nephew in our lives ever again.

Both of my daughters played competitive and high school sports in Oak Creek, and I was unaware of the risk of Sudden Cardiac Arrest in teenage athletes. I have many friends with children in Oak Creek that are athletes. I know that if myself and my friends would have been educated about the risks of Sudden Cardiac Arrest, we would no doubt have our children get an ECG. There was a CPR class held at Oak Creek High School in honor of Kai after his passing and the turnout was great, which shows me parents want to be educated and educate their children on risks like this.

The loss of Kai has devastated our family and left a hole in our hearts. The death of a loved one never gets easier. You just learn to live with the pain that will never go away. Please don't let another family have to learn to live with that kind of pain. I'm asking you to please pass the Kai 11 bill to help educate and raise awareness but most importantly prevent this tragedy from impacting another family and community and to help save countless lives in Wisconsin.

Thank you,

Melissa Stark

Oak Creek WI

Dear Assembly,

My name is Micaela Hastings. I'd known Kai since before either of us could even remember. Our families grew up inseparable and I've always considered Kai my second little brother. We spent almost every day together as kids playing with our siblings and many of my favorite childhood memories are with Kai and his sister, Kiana. His unexpected passing was earth shattering for me, my family, and all of my friends and loved ones who held Kai so dearly. Kai had everything to offer and everything ahead of him in life was so promising. It's just so heartbreaking that something so preventable had to take that from him and take him from us. I had no idea that cardiac arrest could affect anyone my age, let alone younger. Who would have known that 1 in 300 young adults has some type of undiagnosed heart condition? ... but we all should. We need to do more to identify these issues. Please pass the Kai 11 Bill to prevent this tragedy from impacting another family and community in Wisconsin To the Wisconsin Assembly Education Committee,

Thank you for the opportunity to present my testimonial today, in support of the Kai 11 bill. My name is Vicki, and my son Joey is has known Kai since the 2<sup>nd</sup> grade. I have been a practicing nurse for over 35 years. There are so many things that I could say about Kai. Kai was so full of life, had so much to look forward to, and had such a great future. He gave so much joy to my son Joey and myself, and he will always be remembered and greatly missed. My son Joey originally met Kai while playing basketball for the Upward Program in second grade; they have been great friends ever since. Their lives centered around basketball, sports and friends: I remember so many times that they would look forward to getting "the boys together, and playing pick- up basketball at Grandview Park, then would go to the Dollar Store for candy, then end up at McDonald's for a snack". This was their summer routine. Unfortunately, this would also be the last place and the last memory that they would have with Kai before Kai's cardiac arrest. Their lives were centered on school and the love of sports. Kai's high school class was very special, and had an unusual bond; most were atheletes in multiple sports, and were always there to support each other. When news came of Kai's passing, not only Waukesha North High School affected, but the whole town was affected. Coaches and teams from other high schools would come in busloads to support fundraisers that were held for Kai, and for spreading the word about The Kai Lermer Foundation started by Kai's parents, Mike and Patty. What happened to Kai was also affecting their communities, their schools. As the Kai Lermer Foundation became involved with Heart Smart, an organization that promotes prescreening of youth athletes for undetected cardiac conditions, we were able to hold an event for Waukesha North students this past August of 2020; with funding from the Heart Smart Program, we were able to provide free EKG testing to our students, and discovered students with undiagnosed heart conditions from this one event. As more and more high schools around the community are finding out about the availability of the Heart Smart Program, more schools are interested in having this event at their high schools as well. More funding is needed to support programs such as this, which is why passing the Kai 11 Bill is so important. Sudden cardiac death (SCD) is the most frequent medical cause of sudden death in young athletes. More and more we are hearing in the news of local student athletes succumbing to this disease, which could easily be prevented with early detection and follow up. Because of recent coverage by the media about cases like Kai's, more families and communities are becoming aware of the impact of the risk of sudden cardiac death in our youth atheletes. Too often, symptoms of this disease in our youth are overlooked, or misdiagnosed, as it is assumed that young adults appear otherwise healthy, and testing as simple as a screening EKG is considered over testing. It is because of what happened to Kai that took his life too soon, with great passion in helping to prevent this from happening to another youth athlete, that my son Joey, and I support the Senate 95 Bill, The Kai 11 Bill. With this Bill, we can help future student atheletes at risk to seek medical help before it's too late. Thank you for your consideration.

Sincerely,

Vicki Winship

WI Assembly Education Committee:

Kai was a special human being. His ability to walk into the room and immediately bring everyone else's spirits up is something that I haven't seen anyone else be able to do. Kai impacted every single person he came in contact with - whether he realized it or not.

<u>Many</u> things can be taken away from Kai's short - but amazing - life. But for me (the thing I take away the most) was his positive outlook on everything. Our junior year in high school, Kai and I were on the varsity basketball team together. Neither of us played much, so that left us time to get to know each other pretty well on the bench! This is where I saw his ability to <u>always</u> be positive. We would talk a lot and he constantly made me laugh. What stood out to me was how he could still do that during a blowout loss! No matter what was going on around us Kai was always making the most of life. That ability is what I have tried to replicate most and hope others can too.

This law should be passed. If it can save the life of a son/daughter, a friend, a teammate, or a classmate, then I don't see any reason why there is any debate. Don't let this tragic event happen to any other community. I saw how hurt mine was and I don't want anyone else to have to go through that."

We all concur! Undergoing a very simple screening as part of a required physical exam to help diagnose a deadly condition just makes sense-why wouldn't we for the 1 in 300 young adults who have undiagnosed heart conditions (when currently only 10% of them are caught!)? We *have* to react to this great loss to make things better/safer for future student athletes.

Thank-you for your public service and taking the time to hear, review and consider the significance of passing the Kai11 Bill.

Caden Ramspott – Kai's friend & classmate

Richard Hastings 3800 Stillwater Circle Waukesha, WI 53189 414-350-2097 Rhastings71@yahoo.com

Representative Thiesfeldt (Chair) Representative Kitchens (Vice-Chair) Assembly Committee on Education

May 2, 2021

Support for AB 82, Relating to: information about sudden cardiac arrest during youth athletic activities.

I have many memories of Kai as I have known Kai's family for 15 years and I knew Kai nearly his entire life. I will remember Kai for his contagious smile and laugh, I will remember him for the joy he brought to me and my family, but I will also remember him as a young man that was excelling in every aspect of his life.

My son AJ and Kai only a year apart grew up friends from play dates to family gatherings and while they grew apart in many aspects as Kai went to another school, when we got together for combined family fishing trips, it was just like old times. That's just how Kai was, easy to get along with and he was unquestionably fun to be around. Kai truly knew the importance of family and friendship.

I'm writing today because of my relationship with Kai but sudden cardiac arrest in teens is more common that most people know and I guess that's the point.

My son AJ went to Waukesha West High School where nearly 3 years ago, David Skogman, a student athlete voted one of the 2019 top basketball players in the state, went into cardiac arrest during a game. With the help of an AED at the school and a trained mother and assistant coach, he was resuscitated that day and now plays at the University of Buffalo.

Obviously David and Kai's story had very different ending but you can't help but wonder if they had to.

- What could have been if Kai's parents had only known how common cardiac arrest in teens really is?
- What could have been if they knew the importance of an electrocardiogram?

I'm writing today to ask that a very reasonable step be taken to help prevent this tragedy from impacting another family and another community.

I ask you to pass the AB 82.

Warm regards,

Hoday

**Richard Hastings** 

To the members of the Wisconsin State Legislature,

Please allow me a few moments to talk to you about a young man named Kai Lermer that was a big part of my life and my family member's lives. I met Kai's parents when Kai was just a very young toddler. We were neighbors and quickly became very close friends. Growing up together, Kai and my youngest son AJ were very good friends and even through divorce for both families, Kai and his family stayed close to myself and my family. My ex-husband and Kai's father are close friends and the kids (my 3 and Kai and his sister) spent many fun times together, including vacations. They were close for the last 15+ years and myself and Kai's mother are to this day very best friends. To me she is family.

From the beginning, Kai was a sweet, good natured and kind child. He was a joy to be around. He grew quickly and began to excel in sports. His mother Patty was so proud of his accomplishments and would sweetly brag about him to me many times, which I loved. Kai continued trying new sports, basketball, football and track, and he only got better every year. He was a varsity letter athlete in 3 sports in high school along with being a great student and a wonderful son....so impressive. Near the end of his Junior year, while celebrating time off of school with a basketball game with friends in a local park, Kai collapsed and was rushed to the hospital. The diagnosis was a defective heart valve known as Wolf Parkinson's White Syndrome. No one knew that Kai had this ailment as he was the very picture of physical health to that point. Tragically, once at the hospital, he was unable to be revived. Despite the doctors best efforts, Kai would never recover from the loss of oxygen to his brain. I will never forget Patty calling me, with screams and sobs, choking out the words that they would need to take Kai off life support and she would need to let him go. I rushed to the hospital to be with her as she has no family close by. Those last days in the hospital trying to help my best friend muster up the courage to finally say goodbye to her baby boy were the worst I've ever experienced. It was the most gut wrenching awful time for everyone involved. The pain this family has and is going through is immeasurable. But it is not just the pain of Kai's family and close friends that lingers, the entire community is in mourning. Kai was such a special kid and he touched so many while on this earth ... and many more with his passing. He was always happy, always positive, always well liked. He was inspirational to his peers and admired by teachers and coaches. He was a true gem to all who knew him. To watch his sweet life leave his body in that awful hospital room is something I will never get over, and as you can imagine, for Patty and Mike, and Kai's sister and his whole extended family, it has been the most painful experience ever. So sudden, so tragic, so awful...yet so preventable. What Kai had was a treatable condition, but went undetected despite regular physicals and a healthy active lifestyle and attentive caring parents.

I have learned so much because of this tragedy. Before Kai's passing, I was unaware that the #1 killer of student athletes is Sudden Cardiac Arrest. That shocked me to learn. I didn't know about the risk of cardiac arrest in young adults...I always assumed it was an issue only for the old and unhealthy. I would never have known that 1 in 300

young adults have some type of undiagnosed heart condition and that standard physicals only catch 10% of heart conditions in teens. We need to do more to identify these issues. We protect the head with concussion protocols, now it's time to protect the heart! In honor of Kai his family started the Kai Lermer Memorial Fund. With their efforts, they are raising awareness of these undiagnosed conditions and helping put measures into place that will keep other families from experiencing this kind of profound loss. Please pass the Kai 11 Bill to prevent this tragedy from impacting another family and community in Wisconsin. It is such a small thing, but can be life changing to Wisconsin families.

Thank you for your time.

--Diana Byington 262-271-8077 cell diana.byington@gmail.com

## Assembly Education Committee,

Ann Lamb Testimony Letter:

I just wanted to take a moment to thank you for pushing for this legislation for the EKG's. My son was diagnosed with Wolf Parkinson White syndrome by accident when he was in 5th grade. He was very active in soccer and kept saying his heart was beating superfast. We thought maybe he was just a little out of shape and we kept pushing him, not realizing we could have killed him. The Doctor ordered the EKG and the irregularity was found. The fabulous doctors at children's hospital were able to cauterize the extra electrical current. My sons comment after the surgery was, « So, this is what it feels like to be normal. ». As you are well aware, we are one of the lucky families. There are far too many that needlessly suffer the agony of losing a child. My heart goes out to you and your family. Please know that the word is getting out and hopefully through this legislation more children can be saved.

### To: Wisconsin State Assembly - Education Committee

### From: Ethan Hildebran

A happy memory that I have of Kai was actually from the car ride to Grandview park on that day, March 25<sup>th</sup>, of 2019. I had been out of school with the flu the week before, so I hadn't seen Kai for a while. I picked him up from his house and we drove to the park, catching up on stuff and having lots of laughs. It's small memories like that that really make me miss Kai, just being with him and always laughing. Kai would make even the most boring of times enjoyable, even math and physics class, and that's what I loved about Kai. I never could have prepared myself for what would happen that day at the park. I never would have thought that it would be the last time I ever saw my friend. What happened that day at the park will forever haunt me. I can't describe in words the amount of pain it brought me. Never in a million years would I have thought a heart problem would take Kai away from us, with him being such an active person and aspiring athlete. To think that this tragedy could have been avoided by a simple ekg test hurts me so deeply. I can't stress enough that I wish Wisconsin would've had something in place to warn parents of the importance of ekg testing, a warning that could have saved a family and community so much pain. Kai was such a close friend to so many people. Our community of friends and families was hit so hard by Kai's sudden passing, and there still isn't a single day that passes that I don't think about him. I hope that no family, friends, or community ever has to endure such pain as we did. Please vote to pass the Kai 11 Bill to prevent this type of tragedy from impacting another family, school, and community. Thank you.

Ethan Hildebran

Waukesha WI

#### Dear Legislators,

My son was a classmate of Kai Lermer's at Waukesha North high school. The North community was all stunned and saddened when we learned of Kai's undiagnosed heart disease and subsequent passing. I can't imagine the feelings of sadness and grief that his parents, family members and close friends have gone through since that date, especially knowing that this tragedy could have been prevented if an EKG and heart testing were done during his childhood checkups or high school physicals. Since Kai's passing there have been several more local kids who have gone into cardiac arrest – another Waukesha North high school alumni died October 2019 in his sleep from an undiagnosed heart condition; recently a basketball player at Wisconsin Lutheran collapsed during a basketball game but was able to be revived due to trained professionals in the stands; a 14 year old boy at Brookfield Central high school passed away in his sleep – all caused by heart disease that could have been detected and prevented; and this is only in the Waukesha County area. I don't even know how many other cases are in the state of Wisconsin that we don't hear about. It seems like these occurrences are becoming more frequent, or maybe I just have a heightened awareness of this issue. I had no idea that 1 in 300 young adults has some type of undiagnosed heart condition – can we stop being Democrats vs Republicans and come together and do something good during this godawful pandemic, and pass a bill that would prevent this tragedy from occurring again and devastating other families? I feel terrible about Kai's death, but can you please take action so that something positive comes from this?

Please pass the Kai 11 bill to prevent this tragedy from impacting another family and community in Wisconsin.

Jo Ellen Janiszewski

Concerned parent and mother of Kai's classmate

Dear Assembly Education Committee Members,

#### Joey Winship

2021 March 26th, 2019. I received a phone call that I will remember for the rest of my life. I was informed that Kai had collapsed, at that moment, I didn't know that I would never hear from him again. I felt that I had lost a part of me, I had lost my best friend, my brother. He will always have a place in my heart, I grew up with him by my side and he was taken away from me in an instant. He had an impact on not only me, but the whole community of Waukesha, Wisconsin. Kai was a great student, and a great athlete and his passing will leave a mark on all student athletes across Wisconsin. What hurts me the most, is his death was preventable. Kai may still be here with us today if EKG testing was noted on the WIAA athletic form. We can prevent future deaths of student athletes across Wisconsin by educating parents about EKG testing, whether the Kai 11 Law saves one life or a thousand, we can't pass on this bill knowing that we can prevent this tragedy from happening ever again.

#### Dear Legislators,

Kai was not ordinary. He was one of the funniest kids I knew and had a smile that could light up a whole room. I dearly miss him. I'm happy that I got to grow up with him and wish that he was still with us. I'm lucky to have so many great memories with him such as our sleep overs, playing sports together, and being able to always tease him about how bad the Bears are. It's not always easy to focus on the good times. It still hurts me to this day that I don't remember what my last words to him were and that I never had a true chance to say goodbye to him. He still had much more joy and happiness left to bring to the people that knew him.

This bill can help make sure that the next "Kai" is able to continue to be a pillar of happiness and love. This bill should not only pass due to the emotional trauma that it can prevent to those left behind, but also because an EKG test could be done, just like a physical. This bill would help ensure that an athlete is healthy and able to participate in sports. If this bill were to pass it would help me to find some closure knowing that Kai's death wasn't meaningless but was instead used to save lives and prevent others from going through the same grief that I experienced.

Please pass the Kai 11 bill to prevent this tragedy from impacting another family and community in Wisconsin.

Ben Janiszewski

Class of 2020, Friend of Kai

Dear Wisconsin Assembly Education Committee,

My name is Julia Pockat and I am writing to you today to discuss my experience with health issues and the importance of being able to receive EKG testing. I have suffered from anorexia nerviosa since I was in 4th grade, and despite the risk for cardiac problems, I wasn't given an EKG test until 11th grade.

One of the main signs that I had in regards to heart function was uncomfortable feelings in my chest that would keep me up at night. This started in 8th grade, during one of my worst anorexia lapses, and should have been a great warning sign. I was afraid to tell my parents, but when I finally did, we went to the doctor for a checkup. I talked about how my heart felt funny when I was trying to go to sleep or exercise and I was significantly underweight when I went into the checkup. Instead of getting an EKG, I got blood drawn and told that I was doing okay besides being slightly dehydrated. Considering eating disorders have such a high mortality rate partially due to cardiac problems<sup>[1]</sup>, I believe that I probably should have had an EKG to ensure that my heart was functioning properly.

The first time that I had an EKG done was the day before I got admitted to the hospital in 11th grade. Although my heart looked okay, I was told by doctors that I was lucky that my heart hadn't failed. If I did have a heart problem before that, it is possible that I would not be here today as I had never been tested.

My case is nothing unordinary. Around the country there are many other young people that are affected by eating disorders. Many of these people go undiagnosed, and some who hide their disorder long enough to die of their eating disorder without anyone ever knowing their struggle. Many of those with an eating disorder aren't underweight and eating disorders disproportionately impact athletes<sup>[2]</sup>, which puts athletes that seem healthy at a greater risk of heart problems associated with eating disorders. Sometimes the changes in eating patterns that could signal an eating disorder are viewed as being a result of athletes trying to improve at their sports, or sometimes the signs go completely unnoticed. Requiring EKG testing even just for athletes would ensure that the heart health of athletes is monitored and may help someone with heart problems due to an eating disorder (or any other condition) get help before it is too late.

I have friends who have experienced cardiac problems due to their eating disorders, and I have friends who have nearly lost their lives to it. EKG testing is something that is so often not used even though it is a good tool for ensuring that there are

A final note that I would like to make is that I was one of Kai's classmates. I remember the day that Kai passed so clearly. I had a college class in the morning, but when I went to my locker I saw a large group of kids in my grade crying in the hallway. A social worker even came up to me

to make sure that I was okay, even though I didn't even know what had happened. For the rest of that day, and probably for the next few days I don't think that there was a class period where someone didn't have to leave the room to take a break. Losing Kai not only impacted those who knew him well, but also those who had never talked to him. I personally had only talked to Kai a number of times, but I remember during this time I had a lot of memories of the passing of many friends and family members reemerging in my mind, which caused me and my friends a lot of stress. Kai didn't have to die. Now you have a chance to make sure that another family and community doesn't have to go through the same experience by ensuring that EKG tests are available to more people.

Sincerely, Julia Pockat

References:

Northwestern Medicine. (n.d.). How anorexia impacts your heart. Retrieved from https://www.nm.org/healthbeat/healthy-tips/anorexia-and-your-heart

"Eating disorders & athletes." (2018, April 27). Retrieved from https://www.nationaleatingdisorders.org/eating-disorders-athletes

## Assembly Education Committee Members,

## Kiana Lermer Letter (Kai's Big Sister):

Kai was my younger brother and I would like to start today by reading a goodbye letter that I had written to him...

### Dear Kai,

I have written you plenty of letters but I don't think that I have ever really said goodbye in any of them. Even writing this I don't want to, still, but to heal I know I have to. I know that day we said goodbye but after you didn't come home and a week later seeing your physical body in the hospital bed, monitor playing the long, Mono tone flat-line that goodbye did not feel like closure. Did it hurt little brother? Was it really your time? Were you ready to leave us?

I remember growing up thinking that we would be like Dad and Aunt Missy when we got older. Kids around the same age so they could grow up close like we did with Alanna and Kyla, Holidays together always. When I'm told to think of happy times I can vividly picture us as kids running around carefree. Labor Day parties, family vacations, the hog, even times where you bothered me to no end seem like pleasant memories now. I only wish that I could remember more. In life you taught me lessons of patience, humor, genuine happiness, self-esteem, security and kindness towards others. In death I am learning gratitude, acceptance, humbleness, and faith. I will forever remember you as a goofy, kind hearted person you were and will forever feel your absence. Please give me the strength to except what happened and heal. I love you forever your big sister.

So the question that we are here to answer today is why the Kai 11 bill should be passed. Before I answer with a definitive statement I'd like to first inform you of some of the "why" questions I have to ask myself daily since Kais death.

Why was he taken from my family and his friends so soon?

Why didn't we know?

Why didn't the doctor, in his 16 years of life, once recommend the simple EKG test that would have saved his life?

Why do I have to live with the pain of your absence for the rest of my life?

I have 1 million more questions; there are infinite "what ifs". Losing my brother the way that I did has affected me in ways that would take years to explain to someone who hasn't had the same experience. So to answer the Senates "why", it's so that no other Mother, Father, Sister or family member, so that no other friend, so that no other community ever has to ask themselves any of the heavy weight questions that we are stuck asking ourselves today.

Please work to pass AB82 The Kai11 Bill to help us save young adult lives in WI. To prevent this tragedy from impacting another family.

Best, Kiana Lermer Assembly Education Committee,

Looking back on my favorite memories of early childhood and high school it is hard to find one that doesn't include Kai. Kai always loved to have a good time, was always making jokes, and smiling. I can still look back and think about the winter days where we shoveled off the driveway to play basketball, the sleepovers that we built bonds over, and the Friday night lights where we got to live out one of our childhood dreams. Being able to share these things with Kai is just part of the reason we had such a close friendship. These memories are things that I will carry with me for the rest of my life.

Kai played multiple sports growing up and was always active. Almost all of the time spent together was doing some sort of physical activity. This connection was what allowed us to bond and grow. Whether it was messing around in the driveway or going to basketball practice, Kai was always one of the most athletic and energetic kids. I've played countless games with him and I never would have guessed that there was anything wrong with Kai's heart. This is why it came as such a shock when he suddenly passed away. It made me wonder who else had a condition like Kai's that had gone undiagnosed.

This summer I was fortunate to get an EKG test while at UW. I was very grateful for this experience because of the events that had occurred with Kai. I wouldn't wish what happened to my friend upon anyone. Although I was grateful, I couldn't help to be filled with anger. I was angry because of how quick and seamless the test was. The idea that something that was so simple and could save people's lives wasn't something that was provided to the people around me is what caused this. For this reason, and so nobody has to suffer a loss in their family or community that could possibly be prevented. Please pass the Kai 11 Bill to prevent this tragedy from happening to another family, school, and community.

Sincerely,

Chimere Dike