

our

AUGUST/SEPTEMBER 2024

www.kcourhealthmatters.com

HEALTH

YOUR GUIDE
TO HEALTHY
LIVING

matters

RESEARCHERS RACE
TO FIND ANSWERS

RARE DISEASES

MORE COMMON
THAN WE KNOW

VOTER GUIDE PAGES 6-13

YOUR
VOTE
COUNTS



Making Health Literacy Our Top Priority

Discover trending health topics in every edition.



Scan the QR code at left or
download your personal
copy at: kcourhealthmatters.com

Email: info@kcourhealthmatters.com

Phone: 816.361.6400



Watch for details about our



Celebration in 2025

Thank you for being a part
of our journey.

Ruth Ramsey

Ruth Ramsey, Publisher and CEO

Contents



COVER STORY

Rare Diseases More Common Than We Know

By Dennis Ridenour, President & CEO, BioNexus KC

In the U.S., 25-30 million patients have been diagnosed with one of the more than 10,000 currently known rare diseases. Learn how research in our region is gaining national recognition for excellence in rare disease diagnosis, research and treatment.

NOVEMBER 5, 2024 PRESIDENTIAL ELECTION

7 VOTER GUIDE

What You Need to Know to Vote in Missouri and Kansas. Make preparations now. Know your voting rights, eligibility, requirements and polling place.

SPONSORED BY



Health Forward
FOUNDATION

WWW.HEALTHFORWARD.ORG



VOTER REGISTRATION DEADLINES
MISSOURI: WEDNESDAY, OCTOBER 9, 2024
KANSAS: TUESDAY, OCTOBER 15, 2024



Like us on Facebook

www.facebook.com/kcourhealthmatters

Articles in the magazine do not constitute medical advice. Always consult your physician or healthcare provider before making medical decisions. We do not endorse the views expressed in the articles, advertisements and websites, nor are we responsible for products and services advertised.

Bookmark
kcourhealthmatters.com
on your mobile devices
to stay informed about
trending health news
and information.

14 Exploring How the FDA Approves New Drugs

By Jeanene Dunn, OHM Staff

New drugs must go through stringent reviews and approval processes.

24 How COVID-19 Changed Society

After COVID-19, our daily lives changed forever. It became a new normal.

26 Do You Know Your Rights to Emergency Room Care?

By Jeanene Dunn, OHM Staff

The Emergency Medical Treatment and Labor Act (EMTALA) ensures everyone's access to emergency room care.

28 OUR KIDS MATTER Keep Children Safe Around Guns in the Home

American Academy of Pediatrics
Learn why Missouri has the seventh highest rate of gun deaths in the U.S.

29 MENTAL HEALTH Social Media and Youth Mental Health

The U.S. Surgeon General's Advisory
What can parents and others do to protect adolescents' mental health?

Add Nexus to Your Vocabulary

Nexus means “of or having a central link or connection.” When we are at the “nexus” of something, we are in the middle of it, like standing in the middle of an intersection. In disease research, the nexus brings together known and unknown factors that guide researchers to find ways to slow or cure a rare disease. There are more than 10,000 rare diseases for which there are no cures. In this issue, Dennis Ridenour, molecular biologist and director of Bionexus KC, shares how our region is being recognized nationally for advances in rare disease research, digital health, cancer research, health equity and informatics (information science) (Page 16) .

I also want to remind you of the importance of your “freedom to vote.” Many sacrificed their lives for this freedom. 2024 is an important election year, as we must elect leaders who are qualified and best suited to lead honorably and respectfully. Some of the pressing issues at stake are government transparency, accountability, and a commitment to serving the best interests of all people; access to quality healthcare; educational freedoms; stabilizing the economy; and protecting diversity, equity and inclusion.

If you are not registered to vote, register now! See Page 7 for information on how and where to register and your rights as a registered voter. The deadline to register to vote or update your voter registration information in Missouri to participate in the November 5, 2024 General (Presidential) Election is Wednesday, October 9, 2024. Make your vote count. Voters have an incredible opportunity to shape a future that reflects the nation’s shared values and aspirations! By making informed decisions, we can set the course for a more sustainable and successful future for every family. Let’s seize this pivotal moment to make our voices heard!



We are truly at a nexus in finding cures for rare diseases and stabilizing the democracy of our nation.

Stay informed. Stay healthy.

Ruth Ramsey, Publisher and CEO



P.O. Box 5425
Kansas City, MO 64131
816.361.6400
kcourhealthmatters.com

PUBLISHER
Ruth Ramsey
ruthramsey@kcourhealthmatters.com

**EDITORIAL &
STRATEGIC PLANNING**
Donna Wood
dwood@kcourhealthmatters.com

EDITORIAL ASSISTANT
Jeanene Dunn
jdunn@kcourhealthmatters.com

**HAVING AN EVENT?
HAVE QUESTIONS?**
info@kcourhealthmatters.com

WANT TO ADVERTISE?
info@kcourhealthmatters.com

CONTRIBUTORS
Michael Abbott
Zach Hunt
Mike Lane
Dennis Ridenour
Kevin Wake
Curtis Woods
Shaylee Yount



WE WOULD LOVE TO HEAR FROM YOU.

Send us your suggestions for health topics you would like to see in *Our Health Matters*. Also share what you enjoy about the magazine. Email us at info@kcourhealthmatters.com or write to us at

Our Health Matters
PO Box 5425
Kansas City, MO 64131



DEED hosted the 2024 Brown Girl J.O.Y. (Journey of Yourself) urban youth camp with 108 adolescent and teen girls and 50 volunteers. Girls learned about mental power, physical fitness and nutrition.

Legacy Builders Bold & Determined

A unique relationship was born when the Kansas City, Missouri Alumnae Chapter of Delta Sigma Theta Sorority, Inc., established the Foundation for Delta Educational and Economic Development (DEED), a 501(c)(3) nonprofit organization, in 1998. With extraordinary determination, DEED is strengthening programming and funding to support youth scholarships and community enrichment programs.

While DEED operates as a separate entity through its strategic pillars and governing board, the organization

Sharing educational resources, promoting youth development, advocating for social justice and advancing economic development are DEED's keys to building community and legacy.

boosts and leverages the volunteer capacity of more than 300 Delta members from broad and diverse professions and a host of community partnerships.

In 2015, DEED purchased the historic Athenaeum property at 900 E. Linwood Blvd in KCMO. They renamed it The Delta Athenaeum. It has become a community hub focused on building a stronger and more viable community.

DEED'S PRIORITIES:

2024 Voter Registration and Education: Empowering people to vote is a top priority. DEED trains and mobilizes volunteers to register new voters as well as help them understand the voting process and the impact of their vote.



DEED hosts Voters' Registration at Avila University.

Community Investment: DEED's vision includes a Delta District of affordable housing. Several adjacent properties have been purchased to develop a diverse residential community of affordable, market-rate and special needs housing.

DEED's Delta District Capital campaign welcomes donations to support expanding the building to increase handicap accessibility and community use. For more information and to donate visit: Deedkcmo.org



**900 E. Linwood Blvd.
Kansas City, MO 64109 | 816-800-4363**





YOUR VOTE MATTERS

Every registered voter has earned the right to vote and should embrace the privilege and freedom for a number of reasons.

Representation: Voting allows individuals to have a say in who represents them in government. By casting a vote, citizens can choose leaders whom they believe will best represent their values and interests.

Accountability: Voting holds elected officials accountable for their actions. When politicians know that they need to be re-elected, they may be more likely to listen to the concerns of their constituents and act in ways that benefit the public. If they do not, then it is our responsibility to choose a new leader.

Social Change: By participating in elections, individuals can support candidates and policies that align with their values and vision for the future. Voting can be a powerful tool for advocating for issues such as social justice, environmental sustainability, human rights and equality.

Representation of Diverse Voices: Voting enables diverse voices and perspectives to be heard in the political process. It provides an opportunity for individuals from all backgrounds, including marginalized and underrepresented groups, to have a say in the decisions that affect their lives. By casting a vote, individuals can help ensure that the concerns of all members of society are taken into account by policymakers.

Civic Duty and Responsibility: Voting is considered a civic duty and responsibility in many democratic societies. It is a way for citizens to contribute to the functioning of democracy, uphold the principles of self-governance and help shape the future of their country. By exercising their right to vote, individuals play an active role in determining the direction of their society and upholding the democratic values that underpin it.

Overall, voting is a fundamental right and a cornerstone of democracy. Yes, your vote counts!

VOTER GUIDER

METROPOLITAN KANSAS CITY
WYANDOTTE COUNTY, KS
JOHNSON COUNTY, KS



SPONSORED BY

Health Forward
FOUNDATION

WWW.HEALTHFORWARD.ORG

YOUR VOTE MATTERS

The Kansas City Board of Election Commissioners is committed to maintaining current and accurate voter files, maximizing voter registration and voter turnout efforts, educating the voting public, providing the best possible services and conducting efficient, fair, honest and impartial elections.

It is very important to us to maintain the public trust and demonstrate a high degree of honesty and integrity in all activities. Our staff is a bi-partisan team responsible to the Board of Election Commissioners and through them, to the voting public.

VISIT US ONLINE AT WWW.KCEB.ORG

What You Need to Know to Vote in Missouri

VOTER REGISTRATION REQUIREMENTS

- You are a United States citizen.
- You will be 18 on or before the next Election Day.
- You are a resident of Kansas City within Jackson County.
- You are pardoned, discharged or released from any felony conviction.
- You are not judicially declared incompetent.

HOW TO REGISTER

You must present proof of identity when registering to vote. Valid forms of identification include a driver's license, state identification card, a government ID, or ID from educational institutions.

You may register to vote any time during normal business hours of the Election Board, or during the business hours of one of the permanent registration sites (public libraries and government offices). To vote in a specific election, you must be registered by the fourth Wednesday prior to the election.

Upon request, the Election Board will mail you a registration application, or you may download one from our website at www.kceb.org. When the form is completed and returned to us, you will receive notification of your poll location when the next election is scheduled. After you have voted in an election, you will receive a voter ID card.

IS YOUR VOTER STATUS CURRENT?

- Do you need to change your name?
- Do you need to change your address?
- Do you no longer receive mail from the KC Board of Election Commissioners?

TO CHECK YOUR VOTER STATUS, CLICK ON THE "CHECK YOUR VOTER STATUS" BUTTON AT WWW.KCEB.ORG. IF YOUR VOTER STATUS HAS CHANGED, YOU NEED TO UPDATE YOUR VOTER REGISTRATION.



KANSAS CITY BOARD OF ELECTION COMMISSIONERS

4407 Dr. Martin Luther King Blvd.

Kansas City, MO 64130

Phone: 816-842-4820

Fax: 816-472-4960

Email: kceb@kceb.org

www.kceb.org



TO UPDATE YOUR REGISTRATION

Visit a convenient registration site (public libraries and government offices) and fill out a new registration form, or simply complete the form on the back of your voter ID card and mail the card to the Election Board.

ABSENTEE VOTING

You Can Vote Absentee If You Meet the Following Criteria

- You will be absent from your voting jurisdiction on Election Day.
- You are incapacitated or confined due to illness or physical disability, or caring for an incapacitated person.
- You are restricted by religious belief or practice.
- You are employed by an election authority.
- You are incarcerated, but have retained all your voting qualifications.
- You are a participant in the SAFE at Home program.

APPLY FOR AN ABSENTEE BALLOT

- Requests to receive an absentee ballot by mail must be received by the Election Board by 5 p.m. the second Wednesday before an election. Absentee applications can be found on our website at www.kceb.org and can be mailed or faxed to the Election Board.
- You must return your completed ballot and notarized envelope to the Election Board no later than 7 p.m. the day of the election.
- You may also vote an absentee ballot in person at the Election Board office beginning 6 weeks before an election, until 5 p.m. the day before an election.
- You must reapply for a new ballot for each election, unless you are on the list of permanently disabled voters.

Election Day Information

ELECTION NOTIFICATION

Two weeks prior to an election, the Election Board will mail you a postcard giving the date of the election and the address of your polling place.

Poll Hours: 6 a.m. – 7 p.m.

ID REQUIREMENTS

A Missouri driver or non-driver's license, U. S. passport or military ID are the preferred forms of identification. However, you may also use your voter ID card, a recent bank statement or utility bill.

GENERAL INFORMATION

The Election Board is open Monday through Friday between 8 a.m. and 5 p.m. In addition, we are open the Saturday preceding an election from 8 a.m. to noon.

**YOU MUST REGISTER
TO VOTE BY WEDNESDAY,
OCTOBER 9, 2024 IN ORDER
TO VOTE IN THE
NOVEMBER 5, 2024
ELECTION.**

“Every election is determined by the people who show up.” — Larry J. Sabato

YOUR VOTE MATTERS

What You Need to Know to Vote in Wyandotte County



MICHAEL ABBOTT
Election Commissioner
Wyandotte County
Election Commission
wycovotes.org



“I am focused on education and an open-door approach to elections. I want the people of Wyandotte County to work, volunteer or come down to the Election Office and learn the way elections work. Our door is always open.”

To register to vote in Wyandotte County, you must:

- Be a United States citizen
- Be 18 years of age or older (applicants who will be 18 before the next election are welcome to submit an application)
- Be a resident of Wyandotte County

HOW DO I FIND OUT IF I AM REGISTERED TO VOTE?

Visit the Secretary of State's VoterView (wycovotes.org/voterview).

Your name and birth date must match your registration record exactly. For example, if you registered as William Jones, but search for Bill Jones, no matches will be found.

You may also call the office at 913-573-8500. Provide your name and birth date and we will be happy to look it up in the statewide voter registration database.

KEEP YOUR VOTER REGISTRATION CURRENT

Please update your personal information whenever you change your address, name, or party. To update, visit the “How to Register to Vote in Wyandotte County” section at wycovotes.org.

ON ELECTION DAY: AT YOUR POLLING PLACE

Many people prefer to cast their ballot on Election Day. Polling places are open throughout the county from 7 a.m. to 7 p.m. It takes a few minutes to stop by your assigned polling place to cast your ballot. There are trained election workers available to guide you through the process. The process begins with check-in where an election worker will ask for your name and a photo ID. Most voters use their driver's license, but state law allows you to use other forms, such as:

- Driver's License or ID Card issued by any state or district of the United States
- U.S. Passport
- Student ID Card issued by an accredited Kansas college or university
- U.S. military ID
- Government employee badge or ID
- Concealed carry license issued by any state or district of the United States
- Public assistance ID issued by a municipal, county, state or federal government office



MAIN OFFICE

Wyandotte County Election Office

850 State Avenue

Kansas City, KS 66101

Phone: 913-573-8500

Email: election@wycokck.org

www.wycovotes.org

- An identification card issued by an Indian tribe
- Persons aged 65 or older may use an expired photo ID.
- Active military, voting-age dependents, and overseas civilians and their voting-age dependents are exempt when voting under the provisions of the Uniformed and Overseas Citizens Voting Act.
- Persons with established religious beliefs that prohibit photo ID may be exempt. To claim such an exemption, you must complete a sworn affidavit explaining the religious belief that prohibits being photographed.

Visit wycovotes.org for information about Photo ID requirements and voting early.

HOW TO REGISTER TO VOTE IN WYANDOTTE COUNTY

Wyandotte County residents have several convenient options for submitting a voter registration application.

Online: If you have a current Kansas driver's license or nondriver's identification card, you can register to vote online at: www.kdor.ks.gov/apps/voterreg/home/index

Follow the registration instructions and insert your name, address, party affiliation, etc.

On paper: If you prefer to use a paper form, or don't have a Kansas driver's license or nondriver's identification card, you can easily register using a paper registration form. You can also request that a form be sent to you by calling 913-573-8500, or email election@wycokck.org.

On the Voter Registration Application, a Kansas driver's license or nondriver's identification card number is required. If you do not have either one, enter the last four digits of your Social Security number. If you do not have any of these numbers, write "none" in the box. The number will be used for administrative purposes only and will not be disclosed to the public. K.S.A. 25-2309

2024 General Election

October 15, 2024

Last day to register to vote

October 16, 2024

Advance by mail ballots begin mailing

October 19, 2024

**Advance Voting In-Person begins
(5 Locations)**

October 31, 2024

Public test of voting equipment

November 4, 2024

**Advance In-Person Voting ends
(12:00 Noon at the Election
Office only)**

November 5, 2024

**General Election (Polls are open
from 7:00 a.m. – 7:00 p.m.)**

YOUR VOTE MATTERS

Submit your completed and signed application using one of the following methods: Drop it off at Wyandotte County Election Office during normal business hours or mail it to the address above. You can also scan application and email to election@wycokck.org or fax to 913-573-8580.

In-Person Early Voting: You can cast your ballot in person before Election Day. Visit an office location during the early voting period. Evenings and weekend hours are available to make voting more convenient. Even better, early in-person voting is available to all registered voters and no prior application is required.

The following are early voting locations:

- **Eisenhower Recreation Center**
2901 N. 72nd St, Kansas City, KS
- **Edwardsville City Hall Training Room**
670 S. 4th St, Edwardsville, KS
- **Joe Amayo/Argentine Community Center**
2810 Metropolitan Ave, Kansas City, KS
- **Patricia Diane Kane Community Center**
3130 N. 122nd St, Kansas City, KS
- **Wyandotte County Election Office**
850 State Ave, Kansas City, KS

VOTERS' RIGHTS AND RESPONSIBILITIES

As a Kansas voter, you have the right to:

- Ask questions
- Request a ballot if you are:
 - a United States citizen
 - 18 years or older
 - a Kansas resident
 - registered to vote
- Vote a provisional ballot if your name is not on the voter registration list or if there is another question

about your qualifications to vote

- Vote in an accessible voting place, and request assistance if needed
- Review a sample ballot before voting
- Mark your ballot privately and free from coercion or intimidation
- Receive instructions on how to contact the appropriate officials if these rights are violated
- Receive a ballot if you are in line at the time the polls close
- Obtain up to two replacement ballots if yours is mismarked or spoiled
- Occupy the voting booth up to five minutes if others are waiting
- Have your ballot count if it is cast legally and timely

For information about IN-PERSON VOTING and VOTING IN ADVANCE visit: <https://www.wycovotes.org/how-do-i-vote->



WANT MORE VOTERS INFORMATION?

The KC Media Collective, in partnership with The Kansas City Star, have gathered all the information you need to vote in Jackson, Johnson, Clay, Platte and Wyandotte counties. It's entirely free, and written in concise, easy-to-understand language.

A COMPREHENSIVE 2024 VOTER'S GUIDE IS AVAILABLE IN ENGLISH AND SPANISH AT WWW.KCUR.ORG/KCVOTERGUIDE2024

Support for the Voter Guide includes Kauffman Foundation, Health Forward Foundation and other donors.



KANSAS CITY BOARD OF ELECTION COMMISSIONERS

4407 Dr. Martin Luther King Blvd.

Kansas City, MO 64130

Phone: 816-842-4820

Fax: 816-472-4960

Email: kceb@kceb.org

Felons Restoration of Voting Rights What You Need to Know

Missouri law now requires penal institutions to inform individuals in writing, upon release, about the process and procedure that will allow restoration of their voting rights.

Every voter has a right to participate in the voting process. Each month the Circuit Court provides the Election Board with a listing of people in our jurisdiction who have been convicted of a felony or misdemeanor. This data is used to update the voter registration database.

Individuals convicted of a felony are entitled to have their

voting rights restored upon completion of their sentence, probation and parole, as long as they were not convicted of an offense associated with voting or election fraud. The exception is those convicted of a felony or misdemeanor connected with voting infractions [RSMo.115.133.2.(3)]. In that instance, voting rights cannot be restored.

For more information to complete an application related to restoration of voter's rights, contact the Election Board at 816-842-4820 and visit: <https://www.kceb.org/voters/restoration>

Johnson County Voting Information

For detailed information about voting in Johnson County, KS call 913-715-6800 and visit: www.jocoelection.org

The deadline to register to vote or update your voter registration information to participate in the November 5, 2024 General Election is Tuesday, October 15, 2024.

Johnson County Election Office
2101 E. Kansas City Rd.
Olathe, KS 66061

Exploring How the FDA Approves New Drugs

Lab testing, research and clinical trials help determine risks and benefits.

By **Jeanene Dunn**, OHM Staff

Before prescription and over-the-counter medications can be sold to consumers in the U.S., they must be evaluated to make sure they are safe, effective and work according to the product claims.

As American consumers, we benefit from having access to the safest and most advanced pharmaceutical system in the world. The main consumer watchdog in this system is the U.S. Food and Drug Administration's (FDA) Center for Drug Evaluation and Research (CDER).

The center's best-known job is to evaluate new drugs before they can be sold. CDER's evaluation not only prevents quackery, but also provides doctors and patients the information they need to use medicines

wisely. The center ensures that drugs, both brand-name and generic, work correctly and that their health benefits outweigh their known risks.

HOW THE PROCESS WORKS

Drug companies seeking to sell a new drug in the United States must first test it and send the evidence gathered from their tests to CDER to prove that the drug is safe and works for its intended use. A team of CDER physicians, statisticians, chemists, pharmacologists and other scientists review the company's data and proposed labeling.

Before a drug is submitted to the FDA for approval, the company or sponsor performs laboratory and

animal tests to discover how the drug works and whether it's likely to be safe and work well in humans. Next, a series of tests in people is started to determine whether the drug is safe when used to treat a disease and whether it provides a real health benefit.

If this independent and unbiased review establishes that a drug's health benefits outweigh its known risks, the drug is approved for sale. The CDER doesn't actually test drugs but does conduct limited research in the areas of drug quality, safety and effectiveness standards.

WHAT FDA APPROVAL MEANS

FDA approval of a drug means that data on the drug's effects has been reviewed by CDER, and the drug is determined to provide benefits that outweigh its known and potential risks for the intended population. The drug approval process takes place within a structured framework that includes:

Analyzing the target condition and available treatments: FDA reviewers analyze the condition or illness for which the drug is intended and evaluate the current treatment landscape, which provides the context for weighing the drug's risks and benefits.

For example, a drug intended to treat patients with a life-threatening disease for which no other therapy exists may be considered to have benefits that outweigh the risks, even if those risks would be considered unacceptable for a condition that is not life-threatening.

Assessing the benefits and risks from clinical data: FDA reviewers evaluate clinical benefit and risk information submitted by the drug maker, accounting for any uncertainties that may result from imperfect or incomplete data. Generally, the agency expects that the drug maker will submit results from two well-designed clinical trials, to be sure that the findings from the first trial are not the result of chance or bias.

In certain cases, especially if the disease is rare and multiple trials may not be feasible, convincing evidence from one clinical trial may be enough. Evidence that the drug will benefit the target population should outweigh any risks and uncertainties.

Implementing risk management strategies: All drugs have risks. Risk management strategies include an FDA-approved drug label, which clearly describes the drug's benefits and risks, and how the risks can be detected and managed.

It's important for the public to know that most drugs take years to develop. There are instances when drug companies will seek accelerated approval for certain drugs and treatments.

ACCELERATED APPROVAL

Accelerated Approval can be applied to promising therapies that treat a serious or life-threatening condition and provide therapeutic benefit over available therapies.

Since the Accelerated Approval pathway was established in 1992, many drugs that treat life-threatening diseases have successfully been brought to market this way and have made a significant impact on disease course.

For example, many antiretroviral drugs used to treat HIV/AIDS entered the market via accelerated approval and subsequently altered the treatment paradigm. Many targeted cancer-fighting drugs have come onto the market through this pathway.

Before a drug can be tested in people, the drug company or sponsor performs laboratory and animal tests to discover how the drug works and whether it's likely to be safe and work well in humans.

To learn more about Accelerated Approval, approval designations and other requirements, visit <https://www.fda.gov/drugs/development-approval-process-drugs>

Source: The U.S. Food and Drug Administration



By Dennis Ridenour, President & CEO
BioNexus KC

RARE DISEASE

MORE COMMON THAN WE KNOW
RESEARCHERS RACE
TO FIND ANSWERS

ES

There's a common saying in the rare disease community that "rare is common." By definition, a rare disease impacts fewer than one in 200,000 people in the U.S., but collectively, nearly 1 in 10 have a rare disease. In the Kansas City metropolitan area, that means more than 250,000 people have a rare disease. In the U.S., 25-30 million patients have been diagnosed with one of the more than 10,000 currently known rare diseases, which include many uncommon and ultra-rare conditions, as well as some of the most well-known rare diseases like Amyotrophic Lateral Sclerosis (ALS), Cystic Fibrosis and Multiple Sclerosis.

My journey in rare disease started in early 2015. My wife was pregnant with our third child, and, at our 20-week ultrasound, my son was diagnosed with a congenital heart defect that was "incompatible with life." Theo was born early a few months later

at Children's Mercy Hospital (CMH), and, when he was one week old, was medically flighted to Boston Children's Hospital, where he underwent open heart surgery at 10 days of age. While he was in surgery, CMH called and informed us that they had diagnosed him with a rare condition known as Rubinstein Taybi Syndrome (RTS). Since that day, rare disease has been a thread that has woven itself through every facet of our lives. We have joined a community of patients, families and advocates that is incredibly resilient, generous and empathetic, and has been helpful as our family navigates our journey. Today, Theo is thriving and doing very well. While he is

a wide range of conditions. My interest in genetics and rare disease suddenly became more personal because of my son's diagnosis with a rare disease.

The average time from symptom onset to a diagnosis for a rare disease is 6 years. Knowing what is causing a patient's symptoms has significant benefit: it allows a patient to find their community and others who have gone, or are going through, what they themselves or their families are going through. It also allows the

Genomic Answers for Kids (GA4K) program at Children's Mercy Hospital has made nearly 2,000 rare disease diagnoses since it began and is looking to collect genomic data and health information for 30,000 children and their families over the next seven years to create a database of nearly 100,000 genomes.

mostly nonverbal and must endure weekly physical, occupational and speech therapy, he is an incredibly happy and loving kid who loves nothing more than to watch TV, swing and play with his siblings.

As a molecular biologist by training, I have always had a keen professional interest in DNA, genetics and rare disease. I explored potential career paths that included genetic counseling and medical science liaison, which both involve using one's technical background and expertise to educate patients, families and clinicians on

Where does a family start when they believe a diagnosis is inaccurate or misdiagnosed?

The Children's Mercy Research Institute has embarked on innovative and consequential work to collect genomic data from thousands of patients and their families to search for diagnoses and treatments for kids with rare genetic conditions.

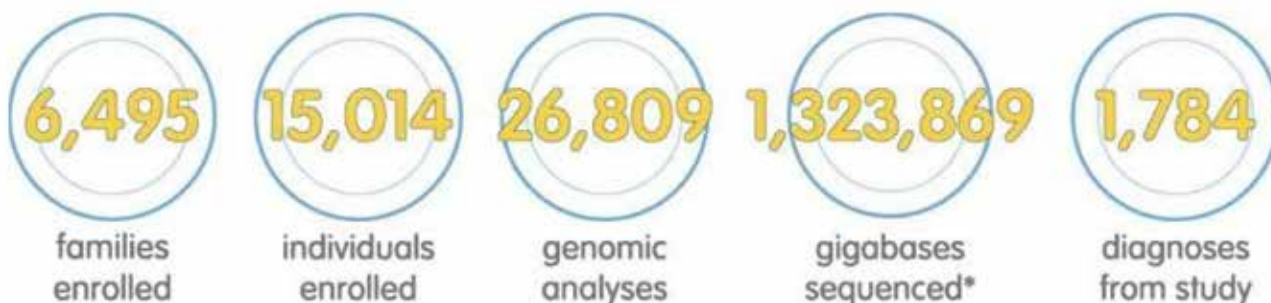
Learn more at: <https://www.childrensmercy.org/childrens-mercy-research-institute/studies-and-trials/genomic-answers-for-kids/information-for-families/>

How does someone go about challenging an undiagnosed or misdiagnosed disease or condition?

Certain red flags may suggest a rare disease or condition that providers have missed. If any of the following sound like what you are experiencing, ask your care team about seeing a geneticist.

- Your symptoms are worsening or not responding to treatment.
- You have new or additional symptoms that don't fit your diagnosis.
- Your disease has a strange presentation, like an early onset or rapid progression.
- You lack the standard risk factors for your diagnosis.
- You have been diagnosed with two unrelated diseases.

For more on red flags visit: sequencedmd.com



Geonomic Answers for Kids Project Progress

We are working hard to make progress for patients with genetic disease.

*Genetic material, or DNA, is made of a string of bases. When we sequence DNA we read these bases. Each gigabase sequenced is 1 billion bases read.

Highlight of Genomic Answers for Kids (GA4K) program at CMH. Sourced from <https://www.childrensmercy.org/childrens-mercy-research-institute/studies-and-trials/genomic-answers-for-kids/>

medical provider to chart a course of care that may include a treatment or cure.

KANSAS CITY IS NATIONALLY RECOGNIZED FOR EXCELLENCE IN RARE DISEASE DIAGNOSIS

Kansas City is gaining national recognition for its excellence in rare disease diagnosis, research and treatment. This can best be demonstrated by the globally recognized Genomic Answers for Kids (GA4K) program at Children's Mercy Hospital, a program focused on using state-of-the-art DNA sequencing technology to identify genetic mutations responsible for an undiagnosed patient's symptoms. The program is building a first-of-its-kind pediatric data repository to help in the search for answers and novel treatments for pediatric genetic conditions. The program has made nearly 2,000 diagnoses since it began and is looking to collect genomic data and health information for 30,000 children and their families over the next seven years to create a database of nearly 100,000 genomes.

WHO IS WORKING ON RARE DISEASE RESEARCH IN KANSAS CITY?

RareKC, a regional nonprofit focused on engaging and supporting patients and driving innovation in rare disease research and care, has been recognized nationally for years as utilizing a best practice method of convening diverse communities within

The average time from symptom onset to a diagnosis for a rare disease is 6 years.

the rare disease ecosystem, including patients, advocates, clinicians and researchers. RareKC's goal is to enhance diversity, equity, inclusion, and belonging with care and research for those affected by a rare disease. Visit RareKC.org

Frontiers, the region's Clinical and Translational Science Institute funded by a five-year, \$25 million grant from the National Institutes of Health (NIH),



Number of Rare Diseases Number of Patients Globally or Nationally that Suffer from a Rare Disease

Sourced from <https://www.globalgenes.org/>

10,000+ Distinct Types of Rare and Genetic Diseases

400 Million People Suffer from a Rare Disease Globally

1 of 2 Patients Diagnosed with a Rare Disease is a Child

3 of 10 Children with a Rare Disease Won't Live
to See their 5th Birthday

is part of a national network of approximately 60 medical research institutions that work together to translate scientific discoveries into advances in patient care. Frontiers funds early-stage research to improve rare disease health outcomes using input from all stakeholders. Visit: <https://frontiersctsi.org/>

BioNexus KC hosts Collaborate2Cure, a series of events focused on convening the various stakeholders of the rare disease community to solve the unique challenges of rare disease both in the clinic and in the lab. Visit www.BioNexusKC.org

In September 2024, **Global Genes**, a national rare disease advocacy nonprofit, will host its annual gathering at the Loew's Convention Center in downtown Kansas City. This conference attracts more than 800 attendees from across the country. This is the first time Global Genes has held its annual meeting outside of San Diego. Visit: www.globalgenes.org

The Society for Craniofacial Genetics and Developmental Biology will host their annual meeting in September at CMH and the Stowers Institute for Medical Research, convening more than 100 researchers from across the globe. Visit: www.scgdb.org

As more and more people make their way to Kansas City, whether for one of the many upcoming conferences

or to find answers during their rare disease diagnostic journey, our region needs to have a coordinated and well-developed plan for engaging and supporting patients and their families. Looking to the future, the KC region has an incredible opportunity to build on our strengths in collaboration and rare disease diagnosis to become a global leader in rare disease care and treatment.

As President & CEO of BioNexus KC, Dennis Ridenour leads regional collaborations for life sciences and healthcare research to improve the health of patients and animals, while reducing and eliminating health disparities. Ridenour has held similar roles at Stowers Institute for Medical Research in Kansas City, MO, Merck Research Labs in Boston, MA, and the Department of Neurobiology at Harvard Medical School.

MORE RESOURCES

NORD Database of Rare Diseases

<https://rarediseases.org/rare-diseases/>

Diversity in Rare Disease

EveryLife Foundation's Rare Diseases

Rare Diversity Hub

<https://everylifefoundation.org/rare-advocates/rare-diversity-hub/>

What You Need to Know About Amyloidosis, a Rare Heart Disease



By Michael Lane

Amyloidosis Army
Patient/Advocate
amyloidosisarmy.org

Amyloidosis is a rare heart disease that predominantly affects older African American individuals, often leading to heart failure. In the black community, 1 in 25 people carry the TTR V122I mutation (transthyretin cardiac amyloidosis) that leads to a rare, incurable, fatal heart disease.

In 2018 I was diagnosed with the rare European mutation T60A, which leads

to the same disease, cardiac amyloidosis, for which there were no approved treatments. My doctor told me I had two years—maybe four—to live. I immediately embarked on a journey to learn everything I could about this disease that was killing me. Since then, some treatments have been approved by the FDA that can extend and improve the lives of those of us who have this disease. I have been fortunate enough to benefit from these treatments and continue to work to bring awareness to this greatly misdiagnosed and underdiagnosed disease.

Amyloidosis is overlooked by most doctors. Some are just not aware of it, so they are not looking for it. If they don't look for it, they won't find it. As a result, the symptoms experienced by many people who have the disease are considered to be from other causes. Without proper screening, diagnosis and treatment, it is a debilitating and fatal disease.

Some of the Signs and Symptoms to Watch for:

- Bilateral carpal tunnel syndrome
- Fatigue and weakness
- Swelling in the legs and ankles
- Shortness of breath
- Numbness or tingling in the hands and feet
- Irregular heartbeat
- Frothy urine

- Unintentional weight loss
- Tongue enlargement
- Easy bruising, particularly around the eyes
- Difficulty swallowing

If you are experiencing any symptoms, ask your doctor for a free screening, which is performed by swabbing your mouth or collecting saliva in a test tube.

I have attended many medical conferences and symposiums on amyloidosis and have heard the best doctors and researchers in the world talk about how the black population has this most prevalent mutation, but no one ever had a real plan to address it. That was hard to accept.

I started Amyloidosis Army in 2024 to increase awareness about V122I in the Kansas City region.



Left to right: Michael Lane; Gregory Patterson, Patient Advocate; and Brett W. Sperry, MD, Cardiologist and Director of St Luke's Amyloidosis Center of Excellence.

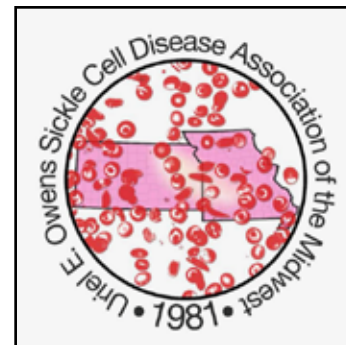


Recently Art Still, a former player for the Kansas City Chiefs (#67), who also has been diagnosed with amyloidosis, joined us.

We host free presentations to churches and civic groups to increase awareness. We feature top cardiologists who share vital information about amyloidosis. To schedule a presentation or for more information, call 816-510-2641 or visit amyloidosisarmy.org.

NEW TREATMENTS FOR SICKLE CELL DISEASE BRING NEW HOPE

September is Sickle Cell Disease Month



By Kevin Wake

President
Uriel E. Owens
Sickle Cell Disease
Association of the
Midwest

Sickle cell disease (SCD) is considered a rare disease throughout the world.

In the U.S. an estimated 100,000 people live with SCD, with African Americans being the most affected population.

WHAT IS SICKLE CELL DISEASE?

Sickle cell disease is a genetic blood disorder that affects the shape and function of red blood cells. Unlike normal red blood cells, which are round and flexible, sickle cells are rigid, sticky and

shaped like a crescent or sickle. This abnormal shape can cause blockages in blood flow, leading to various health complications. Symptoms include:

- Severe and unpredictable pain episodes
- Stroke
- Anemia
- Fatigue
- Frequent infections
- Delayed growth in children

NEW TREATMENTS

Managing SCD requires a comprehensive approach, including regular medical care, healthy lifestyle choices and preventive measures to avoid complications.

Recent advancements in SCD research are offering new hope for more effective treatments. Gene therapy

is a promising area of research aimed at correcting the genetic defect responsible for SCD. In 2023 two new transformative therapies were approved. However, challenges still exist related to insurance costs and limited treatment centers.

HOW CAN YOU HELP

Blood transfusions are a vital part of managing SCD, and having a diverse blood supply is crucial. African American blood donors are especially needed because blood from donors of the same ethnic background is more likely to contain specific markers that are essential for matching and preventing complications in transfusions. The American Red Cross and Community Blood Center regularly emphasizes the need for more African American donors to support patients with SCD.

WHERE TO FIND HELP

The **Uriel E. Owens Sickle Cell Disease Association of the Midwest (Sickle Cell Midwest)** is a local nonprofit dedicated to supporting families in Kansas and Missouri. Our mission is to provide information and awareness about SCD and help people understand where they can receive care and support. We provide emergency financial assistance, referral services, policy advocacy and educational scholarships for patients.

Understanding SCD is crucial for both affected individuals and the broader community. Increasing awareness, encouraging blood donations and supporting Sickle Cell Midwest helps to improve the lives of those living with sickle cell disease.

For more information about Uriel E. Owens Sickle Cell Disease Association of the Midwest call 913-735-2622 or visit www.sicklecellmidwest.org

RARE DISEASE GLOSSARY

FROM COVER STORY PAGES 17-20

Diagnosed

To recognize (something, such as a disease) by signs and symptoms.

<https://www.merriam-webster.com/dictionary/diagnose>

Amyotrophic Lateral Sclerosis (ALS)

Formerly known as Lou Gehrig's disease, ALS is a neurological disorder that affects motor neurons, the nerve cells in the brain and spinal cord that control voluntary muscle movement and breathing.

<https://www.ninds.nih.gov/health-information/disorders/amyotrophic-lateral-sclerosis-als>

Cystic Fibrosis (CF)

A genetic disorder that affects the lungs, pancreas and other organs.

<https://www.cff.org>

Multiple Sclerosis (MS)

An unpredictable disease of the central nervous system. The central nervous system includes the brain, spinal cord and optic nerves.

<https://www.nationalmssociety.org/understanding-ms/what-is-ms>

Congenital Heart Defect (CHD)

One or more problems with the heart structure that are present when a child is born.

<https://www.mayoclinic.org/diseases-conditions/congenital-heart-defects-children/symptoms-causes/syc-20350074>

Rubinstein Taybi Syndrome (RSTS)

A rare genetic disorder that affects many organ systems. RSTS is characterized by growth delays, distinctive facial features, intellectual disability, broad and often angulated thumbs and great toes and feeding difficulties.

<https://rarediseases.org/rare-diseases/rubinstein-taybi-syndrome/>

Molecular Biologist

A scientist who conducts research and experiments on the

molecular and cellular level to better understand how cells function.

www.environmentalscience.org/career/molecular-biologist

DNA

Deoxyribonucleic acid (abbreviated DNA) is the molecule that carries genetic information for the development and functioning of an organism.

<https://www.genome.gov/genetics-glossary/>

Deoxyribonucleic-Acid

Genetics

The branch of biology concerned with the study of inheritance, including the interplay of genes, DNA variation and their interactions with environmental factors.

<https://www.genome.gov/genetics-glossary/Genetics>

Genetic mutations

A change in the DNA sequence of an organism. Mutations can result from errors in DNA replication during cell division, exposure to mutagens or a viral infection. Germline mutations (that occur in eggs and sperm) can be passed on to offspring, while somatic mutations (that occur in body cells) are not passed on.

<https://www.genome.gov/genetics-glossary/Mutation>

Genomes

The entire set of DNA instructions found in a cell. In humans, the genome consists of 23 pairs of chromosomes located in the cell's nucleus, as well as a small chromosome in the cell's mitochondria. A genome contains all the information needed for an individual to develop and function.

<https://www.genome.gov/genetics-glossary/Genome>

Lymphangioleiomyomatosis (LAM)

Lymphangioleiomyomatosis, or LAM, is a rare lung disease that affects women almost exclusively. LAM is characterized by an abnormal growth of cells that can lead to loss of lung function, accumulation of fluid in the chest and abdomen, and growth of benign tumors in the kidneys.

<https://www.thelamfoundation.org/learn-about-lam/what-is-lam/>

How COVID-19 Changed Society

By OHM staff

The COVID-19 pandemic triggered profound changes in society and brought to light the significant gaps within the healthcare system and disaster preparedness in our nation. It also exposed health inequities that underserved communities have been experiencing for decades.

COVID-19 reshaped healthcare delivery, preventive care practices, work dynamics, and many other aspects of daily life. As communities adapt to the new normal, innovation, resilience and collective action are essential in navigating the challenges.

WHAT THE NEW NORMAL LOOKS LIKE Healthcare Delivery

Telemedicine Expansion: The pandemic accelerated the adoption of telemedicine and virtual healthcare services. Patients have increased access to telehealth platforms for consultations with healthcare providers, prescription refills, and monitoring of chronic conditions from the safety of their homes.

Remote Patient Monitoring: Remote management of patients with chronic conditions who require regular monitoring has become particularly valuable, allowing healthcare providers to track vital signs, symptoms and other health data remotely.

Healthcare Digitization: Electronic health records, online appointment scheduling and telehealth integrations have become more prevalent. This process enhances communications between providers and patients and improves access to care.

Vaccinations: The development and distribution of COVID-19 vaccines has underscored the critical role of vaccination in preventing the spread of infectious diseases.

Mental Health Awareness: The pandemic cast a spotlight on heightened levels of stress, anxiety and depression due to social isolation. Mental health teletherapy and mental wellness resources have become more widely available and accepted.

Health Promotion: The pandemic prompted increased health promotion of disease prevention. People now understand how regular physical activity, a healthier diet and managing stress enhances their overall well-being and immune function.

The Workplace

Remote Work Transformation: Many organizations transitioned to remote work arrangements to reduce the risk of virus transmission in the workplace. Video conferencing platforms now offer seamless communication. Some employers allow flexible hours and compressed workweeks. This has improved work-life balance and employee satisfaction.

Workplace Safety Measures: In many workplaces, more stringent health and safety protocols are implemented when management is notified of increased viral infections.

COVID-19 changed all of us for the better by making us aware of the transmission of contagious viruses and ways we can protect ourselves and our loved ones.

Staying Up to Date with COVID-19 Vaccines in 2024

The Centers for Disease Control (CDC) recommends these 2023–2024 updated COVID-19 vaccines—Pfizer-BioNTech, Moderna, or Novavax—to protect against serious illness from COVID-19. Everyone aged 5 years and older should get 1 dose of an updated COVID-19 vaccine to protect against serious illness from COVID-19. Ask your doctor about scheduling the latest vaccines.

Source: CDC.gov

KCGP and 20/20 Leadership took high school students on an educational tour of City Hall to get an up close look at city government and Mayor Quinton Lucas' office.

EMPOWERED YOUTH BUILD BETTER COMMUNITIES

Stanley Taylor, Jr.
Co-Founder & Program Strategist

“Education is the most powerful weapon which you can use to change the world.” – Nelson Mandela

In 2016, Kids Community Growing Prosperity (KCGP), a 501(c)(3) nonprofit organization, took decisive action to ensure that youth in urban areas of Kansas City succeed. They established three programs to address the needs of youth and young adults ages 15-25. Three key areas—Civic Engagement, Social Entrepreneurship, and Health Awareness—provide the tools youth need to achieve personal goals and make positive contributions to their community.

Civic & Community Engagement— The Keys to a Successful Life

Civic engagement is the driving force behind social justice and a strong democracy. KCGP provides urban, disadvantaged youth with the tools they need to reach their full potential. Over 5,000 community service hours have been completed through youth-led programs.

Projects & Initiatives include:



Voter Education: Democracy depends on citizen participation. At the “I’m Proud to Vote” Rally, KCGP’s youth collected approximately 2,400 Voter Information Cards and explained the importance of participation in the voting process.

Parent Engagement: KCGP parents received certificates for their participation in the Parent Power Lab, which effectively trains parents on how to engage with teachers and school systems.

Advocacy: Students wrote letters to the city government about their concerns, which helped foster a sense of involvement on local issues.

Social Entrepreneurship: Youth develop financial literacy skills to take charge of their financial futures, leading to greater stability, security and overall well-being.

Health Awareness: Youth learn skills to take charge of physical, mental and behavioral health, which contributes to positive civic engagement and self-esteem.

KCGP needs volunteers and donations to continue expanding programs to serve more youth. To get involved email: info@kcgpnprofit.org.



Kids Community Growing Prosperity

To get involved email: info@kcgpnprofit.org | kcgpnprofit.org

AD SPONSORED BY
 **Health Forward**
FOUNDATION
WWW.HEALTHFORWARD.ORG



What You Need to Know About Your Right to Emergency Room Care

By Jeanene Dunn *OHM Staff*

Hospital emergency departments are a critical component of the American healthcare system. They are the main point of entry for millions of uninsured, acutely ill and seriously ill patients. Emergency room doctors and nurses provide care to any patient who walks through the door. That right is ensured by the law Congress passed in 1986—The Emergency Medical Treatment and Labor Act (EMTALA).

What is required under the law

Hospitals that receive Medicare funding and maintain an emergency department have three main obligations as mandated by EMTALA:

1. For any person who comes to a hospital emergency department, the hospital must provide an appropriate medical screening examination to determine whether or not an emergency medical condition exists.

2. If an emergency medical condition exists, the hospital must stabilize the medical condition within its facilities or initiate an appropriate transfer to a facility capable of treating the patient.
3. Hospitals with more specialized capabilities are obligated to accept appropriate transfers of patients if they have the capacity to treat the patients.

These criteria must be met regardless of the patient's insurance status or ability to pay, and care must be provided without delay.

Walk-in clinics or urgent care facilities do not fall under the EMTALA because they do not provide emergency services.

to an emergency department to include those arriving on a "hospital campus," defined as the physical area up to 250 yards from the main hospital building, including parking lots, sidewalks, administrative entrances, and areas that may bypass the emergency department, such as labor and delivery.

Transfer requirements

A patient with an emergency medical condition may be transferred only after screening and the provision of stabilizing treatment.

Four requirements must be met:

- The transferring hospital minimizes the medical risks (and in the case of a woman in labor, the medical risks of the fetus as well).
- The receiving medical facility has available space and qualified personnel for the treatment and agrees to accept the transfer.
- The transferring hospital sends all medical records related to the emergency condition that are available at the time of the transfer and any other records not yet available as soon as practicable.
- The patient is transferred using appropriate personnel and transportation, including the use of necessary and medically appropriate life support measures during the transfer.

What constitutes an emergency medical condition?

An emergency medical condition as defined by EMTALA is "a condition manifesting itself by acute symptoms of sufficient severity (including severe pain), that without medical intervention could place the person's health in serious jeopardy."

The "emergency department" extends outside of the emergency room

In 2003, the U.S. Department Health and Human Services broadened the definition of a patient presenting

to an emergency department to include those arriving on a "hospital campus," defined as the physical area up to 250 yards from the main hospital building, including parking lots, sidewalks, administrative entrances, and areas that may bypass the emergency department, such as labor and delivery.

EMTALA compliance is regulated by the Centers for Medicare & Medicaid Services (CMS), a division of the U.S. Department of Health and Human Services (HHS). Anyone can file an EMTALA complaint with the State Survey Agency. This agency will investigate the issue and verify corrective action to ensure the hospital is in compliance with EMTALA. To learn more, visit: [cms.gov](https://www.cms.gov) (search for health quality safety standards)

Sources:

[cms.gov](https://www.cms.gov) – The Centers for Medicare and Medicaid Services
[emra.org](https://www.emra.org) – Emergency Medicine Residents' Association



KEEP CHILDREN SAFE AROUND GUNS IN THE HOME

Did you know that roughly a third of U.S. homes with children have guns? In fact, an estimated 4.6 million kids live with unlocked, loaded guns. That's a scary statistic when you think about the fact that even young toddlers are capable of finding unlocked guns in the home, and they are strong enough to pull the trigger.

As a parent, you may not realize what a serious risk a gun in the home is, especially for children.

Firearms are now the leading cause of death for U.S. children and teens under the age of 18. And the reality is that having firearms in the home increases the risk of unintentional shootings, suicide and homicide. Learn how to keep your child safe.

THE MOST EFFECTIVE WAY TO KEEP KIDS SAFE

According to the American Academy of Pediatrics (AAP), the safest home for a child is one without guns. The most effective way to prevent unintentional gun injuries, suicide and homicide to children and adolescents, research shows, is the absence of guns from homes and communities.

WHAT TO DO IF YOU KEEP A GUN IN YOUR HOME

If you decide to keep guns in the home, be aware that many studies show that teaching kids about gun safety, or to not touch a firearm if they find one, is not enough. You can reduce the chances of children being injured, however, by following important safety rules.

SAFE GUN STORAGE

All guns in your home should be locked and unloaded, with ammunition locked separately. Make sure children and teens can't access the keys or combinations to lock boxes or gun safes. And remember not to keep loaded, unlocked guns in the car, or anywhere else on your property.

Keep the "safe" in firearm safety

Hiding a gun is not enough! Kids are curious, and studies show they usually know where a family keeps a gun.

Gun safes can lower the risk a curious child will be hurt:



Safe or lockbox
for handguns



Locked gun
safe for rifles



Gun trigger locks—
inexpensive and effective



Lock box
for ammo

healthychildren.org
Provided by specialists, trusted by parents.
Not for medical advice or treatment.

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN

TALK WITH YOUR CHILDREN ABOUT GUNS

Remind your kids that if they ever come across a gun, they must stay away from it and tell you immediately.

Source: American Academy of Pediatrics,
<https://www.aap.org>

MISSOURI HAS THE SEVENTH HIGHEST RATE OF GUN DEATHS IN THE U.S. and is missing all of the foundational gun safety laws including a secure gun storage law, requiring background checks for all firearm sales and requiring a permit to carry concealed firearms in public. The state also lacks a law requiring gun owners to securely store their firearms. — everytownsupportfund.org.



United States Surgeon General Dr. Vivek Murthy

SOCIAL MEDIA POSES RISKS TO MENTAL HEALTH OF CHILDREN AND ADOLESCENTS

In May 2023, United States Surgeon General Dr. Vivek Murthy released a new *Surgeon General's Advisory on Social Media and Youth Mental Health*.

With adolescence and childhood representing a critical stage in brain development that can make young people more vulnerable to harms from social media, the Surgeon General is issuing a call for urgent action to maximize the benefits and minimize the harms of social media platforms and create safer, healthier online environments to protect children. "Children are exposed to harmful content on social media, ranging from violent and sexual content, to bullying and harassment. And for too many children, social media use is compromising their sleep and valuable in-person time with family and friends," according to Dr. Murthy.

While social media may offer some benefits, there are indicators that social media can also pose a risk of harm to the mental health and well-being of children and adolescents. Social media use by young people is nearly universal, with up to 95% of young people ages 13-17 reporting using a social media platform, and more than a third saying they use social media "almost constantly."

Social media can become harmful depending on the amount of time children spend on the platforms, the type of content they consume or are otherwise exposed to, and the degree to which it disrupts activities that are essential for health. Additional harms include:

- Experiencing poor mental health outcomes
- Symptoms of depression and anxiety
- Body dissatisfaction
- Disordered eating behaviors
- Social comparison and low self-esteem
- Addiction to certain social media platforms (over half of teenagers report it would be hard to give up social media)

Steps parents and caregivers can take to protect children

Create tech-free zones. Restrict the use of phones, tablets and computers for at least one hour before bedtime and through the night. Keep family mealtimes and in-person gatherings device-free.

Model responsible social media behavior. Set good examples of what responsible and healthy social media use looks like by limiting your own use. Be mindful of how you share information about your child.

Report cyberbullying and online abuse and exploitation. Tell your child to report to you immediately if he or she is being harassed through email, text message, online games, or social media or have been contacted by an adult seeking private images or asking them to perform intimate or sexual acts. Report cyberbullying to local law enforcement. To learn more, visit [CyberTipline.org/Take it Down](https://www.cybertipline.org/Take-it-Down).

To read the full report, visit: www.hhs.gov/surgeongeneral/priorities/youth-mental-health/social-media/index

WHAT'S NEXT?



OCTOBER 2024

CANCER DIAGNOSIS? YOU ARE NOT ALONE

The National Cancer Institute definitively reports that new cancer cases are on the rise. In 2022, there were 1.9 million cases. In 2023, that number surpassed 2 million.

IN THIS EDITION, WE UNCOVER THE ROOT CAUSES OF THE GROWING PREVALENCE OF “EARLY-ONSET” CANCERS DIAGNOSED IN ADULTS BETWEEN THE AGES OF 18 AND 49.

We explain who should consider genetic testing for inherited cancer risk, what happens after you receive a cancer diagnosis and what types of aftercare are available to ensure one's physical, mental and spiritual needs are met. We remind readers to practice prevention, which includes eliminating tobacco use, being physically active, adopting healthier diets and more. As we look forward to the November elections, we must reflect on what matters and what will make our families healthier and our country more civil to ensure a better future for everyone.

**INCREASE YOUR EXPOSURE
AND EXPAND YOUR BUSINESS.
ADVERTISE IN OUR *HEALTH MATTERS*™**

If you are looking to reach new customers and foster lasting relationships, call 816.361.6400 or email your request to info@kcourhealthmatters.com.



THE BLAQUE VOTE

MAKING SHIFT HAPPEN



WE ARE BLAQUE KC

Black Leaders Advancing Quality Urban Education is a grassroots movement of parents, teachers, young leaders, and advocates unapologetically focused on improving the academic, economic, social, emotional and life outcomes of Black children in public schools.

We are empowering a new generation of leaders in Kansas City, equipping them with the tools to advocate effectively for our children. Our fight for quality education for Black students relies on the strength of our community, amplifying the voices of parents, teachers, and civic leaders.



WELCOME TO THE FOREFRONT OF CHANGE!

The BLAQUE Vote Fellowship is a 9-month civic engagement program for college students on local college campuses. BLAQUE KC believes in the power of voting and aims to empower young people to actively participate in democracy.

The fellowship demystifies the voting process and promotes legislative understanding through hands-on learning, community engagement and direct involvement in advocacy. Students will undertake real-world learning tasks to apply their knowledge. For instance, after learning about local government structures, they will attend relevant meetings, identify issues affecting them, and communicate with elected representatives.

Sessions include:

- UniversITEA Politics
- Understanding National, State, and Local Systems of Government
- Unpacking the Legislative Process
- Voter Education and ID Requirements
- Organizing Movements
- Crafting Policy for Change



BROADENING HORIZONS WITH TRAVEL OPPORTUNITIES

Scholars will explore history and inspire change! The BLAQUE Vote kicks off with an unforgettable trip to Montgomery, Alabama, where you'll trace the footsteps of our ancestors and witness the pivotal moments that shaped our nation.

Highlights of the Trip:

- Edmund Pettus Bridge: Walk the path of courage and resilience where the Selma to Montgomery marches ignited the fight for civil rights.
- The Legacy Museum: Immerse yourself in the powerful story of African American history, from enslavement to mass incarceration.
- The National Memorial for Peace and Justice: Reflect on the legacy of racial injustice and honor those who fought for equality.



How You Can Support!

Are you politically involved? Want to help inspire the next generation of SHIFT Starters? Scan the QR code to fill out the form to tell us how you want to be involved!

Having trouble with the QR Code? Email Sabrina Dowdy at sdowdy@blaquekc.com

Together, we can empower the leaders of tomorrow and create a brighter, more equitable future for our community. Your support is crucial in driving the change we strive for.



Investing in our youth is an investment in our collective future. At BLAQUE KC, we strive to cultivate a generation of informed voters who understand the power of their voices. When young adults engage in the electoral process, they catalyze progress and transformation within our communities. By empowering them with knowledge and encouraging their active participation, we can create a more just and equitable society. The impact of their votes extends beyond the polls, influencing the very fabric of our democracy.

Join us in our mission to engage collegiates in the electoral process. Scan the QR code to let us know how you can support The BLAQUE Vote.

-Dr. Cokethea Hill
CEO & Founder
BLAQUE KC

AD SPONSORED BY



WWW.HEALTHFORWARD.ORG





Download Digital copies of Our Health Matters™ at:
<https://kcourhealthmatters.com/digital-editions/>
Be sure to FOLLOW US on Facebook and Instagram

  @kcourhealthmatters

Contact us at: info@kcourhealthmatters.com
Call 816-361-6400

CALL 911 IF YOU ARE EXPERIENCING A MEDICAL EMERGENCY

CALL 988 to reach a trained crisis counselor who can help in a mental health, substance use or suicide crisis.