

It's About Children

DEC 2019

SPECIAL EDITION
ANNUAL REPORT
2018 - 2019

meet
Jaxson

FREE
HEIGHT
CHART
inside



EAST TENNESSEE
Children's
Hospital
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More than a number

by Madison Murray & Leandra Wilkins

When the Cope family goes to count their blessings, they count one 5-year-old, one extra chromosome and one Children's Hospital.

Five-year-old Jaxson lives with a rare genetic condition called trisomy 9q. He was born with part of an extra chromosome, which his doctor in the Neonatal Intensive Care Unit (NICU) at East Tennessee Children's Hospital was able to diagnose early. Within two weeks of welcoming their son into the world, new parents Rachael and Drew learned that Jaxson's often-fatal condition is so rare, there isn't much research on treating it. Luckily, they have a team of experts at Children's Hospital to help them face every new challenge.

Trisomy-what?

Trisomy 9q occurs when the entire 9th chromosome appears three times rather than twice in some cells. One segment of the chromosome (Q) is in duplication. Among other things, the disease causes an array of developmental disorders and malformations that vary from patient to patient.

In Jaxson's case, he was born with a blockage in his digestive tract, which required multiple surgeries at Children's Hospital. He still requires a gastrointestinal tube (G-tube) for feeding, but he attends weekly therapies to learn how to swallow and eat on his own.

Jaxson also has some developmental delays. He did not learn to walk until he was 26 months old, but now he runs and jumps like any other five-year-old. And although he is unable to speak, Jaxson has found a way to communicate through sound and sign language.

Although there is little information on trisomy 9q, the Copes are encouraged by the patient-focused care they receive at Children's Hospital.

"We are writing our own rulebook with Jaxson and Children's Hospital has helped us do that," says Rachael.

A miracle baby

Jaxson came into this world early, a week before Christmas, but his journey could have ended before it began.

In the final stages of pregnancy, Rachael suddenly lost her amniotic fluid, which is the nutrient-rich fluid surrounding the baby in the womb. Typically, a baby who loses its central source of nutrients wouldn't survive, but Jaxson miraculously did. It wasn't until after Jaxson was born that the Corryout couple realized the intestinal blockage caused by his rare trisomy 9q was most likely what saved his life in the womb.

"He's our miracle baby. This thing that has caused so many problems is also the thing that saved his life." - Drew Cope

Following his premature birth, Jaxson spent 70 days in the NICU, fighting for life. The Copes worked with their primary care team to create a road map for Jaxson.

"We worked through Jaxson's care little by little, one day at a time," says NICU nurse Elizabeth Cayce.

Because of his fragile state, Rachael and Drew were unable to hold Jaxson until nearly ten weeks later. One snowy morning, just days before they were scheduled to be discharged from the NICU, Elizabeth offered the family the greatest gift she could: a chance to hold their son for the first time.

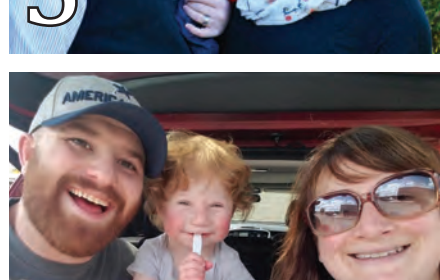
"It was our first Christmas present as parents, and that was all we could have asked for," says Drew.

Shining his light

Living with a rare genetic condition can be intimidating, but because of his parents' attentive dedication, Jaxson is thriving. In his first four years of life, Jaxson has had 12 surgeries, made numerous inpatient stays for various illnesses, and has had more than a few trips to the Children's Hospital emergency department. He lives with a feeding tube and attends up to three hours of therapies per week.

"Jaxson does have a lot of medical issues related to his medical disorder," says Dr. Kelly Boggan, Jaxson's pediatrician, "but he's certainly up to the challenge."

Dr. Boggan has worked with the Copes since Jaxson was released from the NICU. She coordinates his care between her practice at Children's Hospital Primary Care and the many specialists he sees at Children's Hospital.



"Even from that very first visit at two months of age, he just had this smile that steals your heart," says Boggan.

Jaxson has touched nearly every department at Children's Hospital so far. From the emergency department to the inpatient floors, nurses and doctors will make a special effort to visit with the bouncy redhead and his parents.

Jaxson is admitted to Children's Hospital at least once a year, and in those instances, the nurse who knows him best volunteers to be his primary nurse, so that he and his parents have consistent, familiar care.

"I really love Rachael and Drew," Elizabeth says. "They're awesome parents, and Jaxson is so fun to take care of."

Jaxson's personality is magnetic. "Even if you have never met him before, you are bound to fall in love with him," adds Rachael.

Jaxson's Journey

1. Jaxson spent 70 in the NICU at Children's Hospital - 2. Jaxson takes a ride in his favorite red wagon - 3. The Cope family has spent 3 out of 4 Christmases at Children's Hospital, battling life-threatening conditions - 4. Jaxson's parents are writing their own rulebook for his rare genetic disorder - 5. Dr. Boggan, Jaxson's primary care physician, coordinates the many specialists and therapies Jaxson needs to reach his fullest potential

What's next?

What does the future hold in store for Jaxson?

"All we want for Jaxson is for him to live a happy life," says Rachael. She and Drew work tirelessly with Jaxson on his language and motor skills and the lessons they receive in his speech and physical therapies. They have also enrolled him in pre-K at a local school that offers inclusive special needs classrooms. That means Jaxson can learn and develop with children his age, regardless of disability. Since starting school, Jaxson has blossomed even more into his bright personality.

Thanks to the occupational therapy he receives, Jaxson has started to learn how to eat solid foods and will eventually have his G-tube removed. It is unknown whether Jaxson will gain the ability to speak, but his parents are determined to help him develop his communication skills to their fullest potential.

"Jaxson will always struggle with development and growth problems, but he has already come so far in his five years," says Dr. Boggan. "The sky is the limit with him."

Jaxson's extra chromosome has brought with it an added brightness to his family.

Jaxson continues to thrive and impact everyone he meets. He's leaping through milestones and changing the way trisomy patients are treated. East Tennessee Children's Hospital is proud to have been a home for Jaxson during his most fragile times. As he continues to grow, the hospital will always be there to welcome him with open arms for routine checkups or just a smile.

2019 HOSPITAL HIGHLIGHTS



Recognized nationally as Solutions for Patient Safety Hospital of the Month (June 2019). This is the 3rd time Children's Hospital has been ranked above other children's hospitals for patient safety.



Children's Hospital earned an A/Stable rating from 2 of the 3 top credit rating agencies in the U.S.



"You don't see numbers like this often." The Joint Commission surveys our hospital every three years to evaluate our safety and quality of care. In 2018, we passed with flying colors.



Attorney Alex Brinson helped more than 200 patient families with needs like housing, education, benefits and family law. This service is offered from the hospital and is free to families.



SPECIALTY CARE

Children's Hospital expanded to offer more focused, multi-disciplinary treatment and better ease of access to patients with sickle cell anemia, genetic conditions, and chest wall deformities.



EXPANDED ACCESS

Children's Hospital opened its second urgent care center in April 2019. Located in Powell, Emory Center also offers rehabilitation therapy services during the day. For more information, visit childrenshospitalurgentcare.com



IN YOUR COMMUNITY

In 2019, we launched Children's Hospital Pediatrics. At thirteen partner practices across East Tennessee, you may see a new name, but you'll receive the same great care.



HELP ON WHEELS

This year, the hospital purchased a new LifeLine ambulance, to replace an outdated model. This mobile intensive care unit travels to 25 hospitals throughout East Tennessee, Kentucky and Nashville.

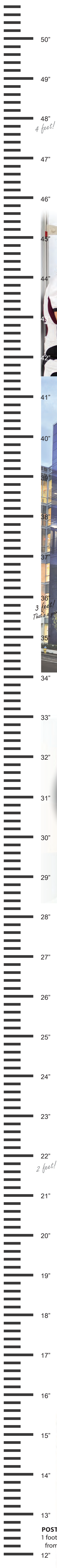


EAST TENNESSEE
Children's Hospital

2018 Clinch Ave
Knoxville, TN 37916
www.etch.com

2018-2019 ANNUAL REPORT

RAISING HEALTHY CHILDREN TOGETHER
Use this height chart to keep track of your child's growth.



5,454
Hospital Admissions
-3% from 2018

432
PICU Patients
-7% from 2018

927
NICU Patients
+10% from 2018

CLINICAL STATS

Chemotherapy treatments	2,618
Breathing treatments	194,935
X-rays	43,569
MRIs	3,547
CTs	5,397
Ultrasounds	8,194
Lab tests	383,933
Sleep studies/visits	1,206
Transports from other hospitals	949
Hours of family support by chaplains	3,500
Families helped by Interpretive Services	8,575

OUTPATIENT STATS

120,855 Outpatient Visits (-14% from 2018)

19,105 Rehabilitation Center Visits (+10% from 2018)

30,162 Home Health Visits (-16% from 2018)

59,194 Emergency Department Visits

13,517 Urgent Care Visits

72,711 Emergency & Urgent Care Visits (+12% from 2018)

210 Babies treated for drug dependency
493 participated in *Grow With Me Clinic*, an innovative program that helps address the many needs of children born with neonatal abstinence syndrome (NAS) from birth to age 5



2,123 Employees

Andrew, age 17, sports physical MVP, with nurse Misty

9,762 Surgeries (-8% from 2018)

396 Physicians

32 Specialties
More than any other hospital in the region

18,574 Child Life Visits

7,904 Family Encounters by Social Work

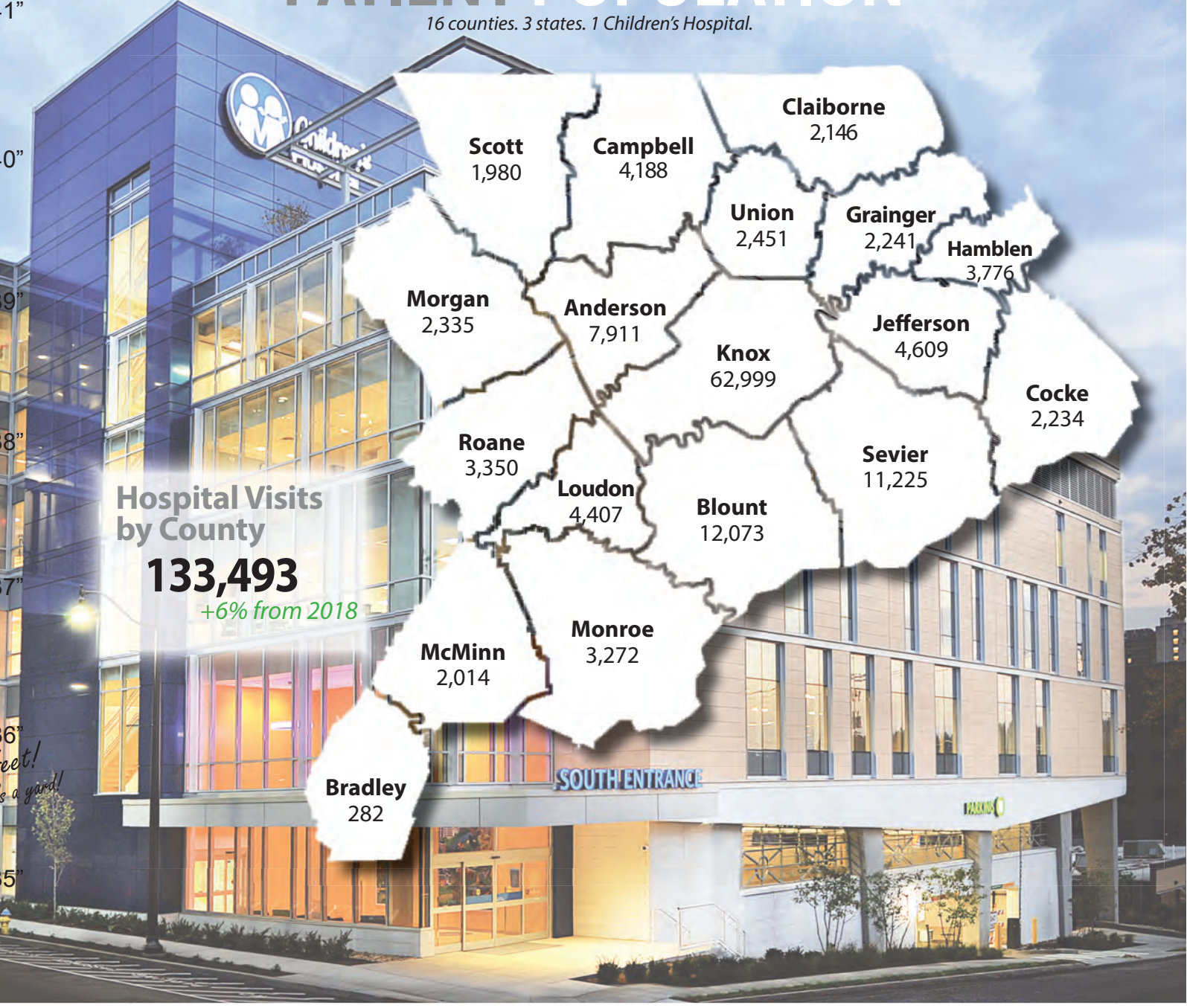
1 Facility Dog

45,269 Volunteer Hours

Top 3 languages translated
Spanish, Arabic, Swahili

PATIENT POPULATION

16 counties. 3 states. 1 Children's Hospital.



COMMUNITY BENEFIT

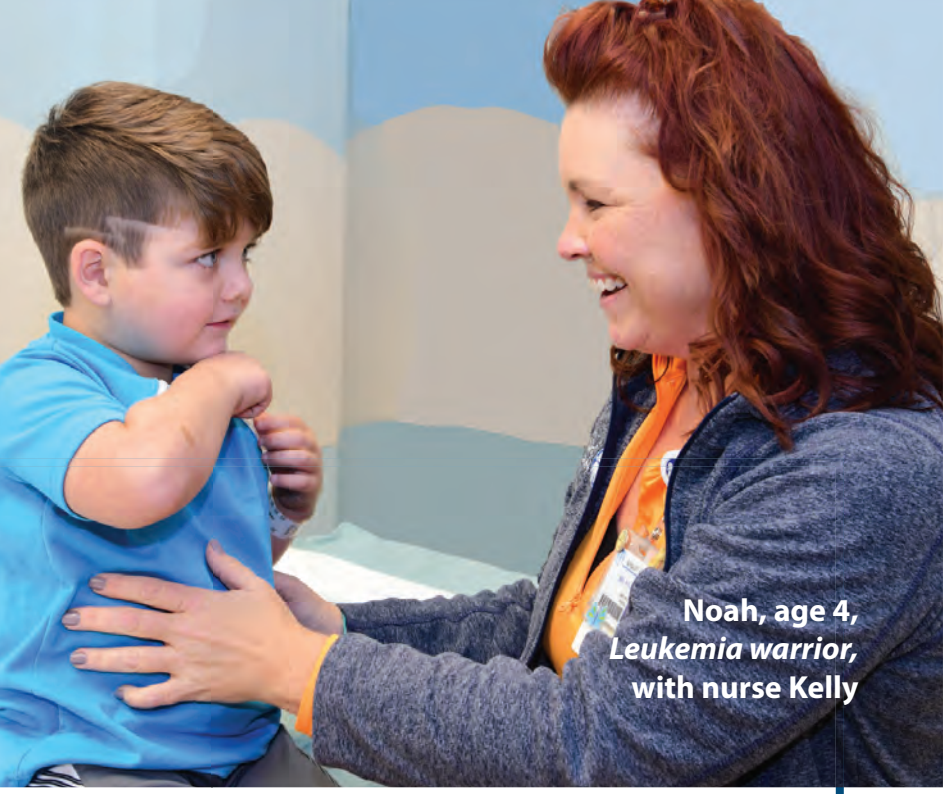
As a non-profit organization, Children's Hospital invests millions of dollars each year to improve our community.

Total community benefit	\$4,330,100
Research	\$188,759
Community-building, health & safety	\$85,114
Education of medical students, residents and health professionals	\$1,732,452

UNDER-COMPENSATED CARE*

Uncompensated	\$9,327,492
Charity Care	\$2,905,000
Bad Debt	\$3,650,936

*The cost of treatment provided to those who cannot or do not pay, whether it's with insurance, Medicare/Medicaid, or from their own pockets.



Noah, age 4, Leukemia warrior, with nurse Kelly

COMMUNITY OUTREACH

Blood drives conducted at hospital	4
Health fairs and presentations	8
Children attended our summer camps	147

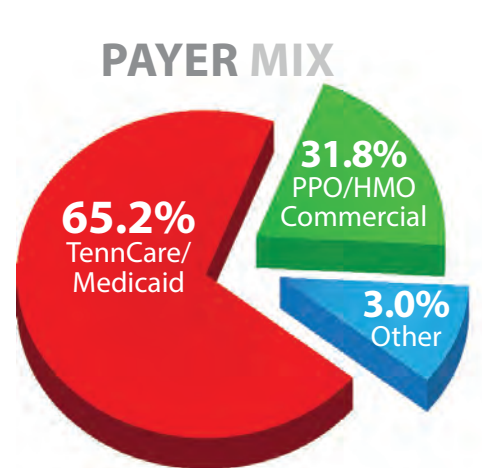
WELLNESS

Children involved in activities/programs to improve nutrition and commitment to physical activity	5,083
Children screened for asthma	526

SAFETY & INJURY PREVENTION

Schools served by Project ADAM programs	178
Individuals trained to administer CPR in schools	1,203
Helmets distributed	2,517
Car seats inspected	2,111
People reached by Water Safety campaign	24,771
People reached by Car Seat and Heat Stroke campaign	11,547

2019 FINANCIALS



DONORS
Total Raised **\$6,985,042**
Number of Donors **5,869**
All donations help offset cost of state-of-the-art medical equipment, building improvements and programs.

FUNDRAISING EVENTS



RADIATION

These events raised more than \$1 million to purchase life-saving medical equipment for Children's Hospital.

PROVIDER CHANGES 2019

Retirements

John Howick, Jr., MD (27 years, Neonatology)
Stephen Prinz, M.D. (44 years, Neonatology)

In memory

Joe W. Black, III, M.D. (1959 - 2019)

Welcome

- | | |
|---|--|
| Sarah Bateman, N.P. (Neurology) | Jodie Manross, L.Ac. (Acupuncture) |
| Matthew Blair, M.D. (Urgent Care) | Liane Potter, N.P. (Neonatology) |
| Melanie Bodine, N.P. (Neonatology) | Amy Pouliot, P.A. (Neurosurgery) |
| Mari Eaton, M.D. (Neonatology) | Jonathan Rothenour, P.A. (Emergency Medicine) |
| Bryan Eriksen, M.D. (Neonatology) | Elizabeth Roehner, C.R.N.A. (Anesthesiology) |
| Sarah Beth Eriksen, M.D. (Pediatrics) | Vanessa Thomas, M.D. (Pediatrics) |
| Kelsey Fredericks, N.P. (Hematology/Oncology) | Jenna Verdell, N.P. (Pediatric Intensive Care) |
| Lauri Gingerich, N.P. (Urology) | Marissa Warwar, N.P. (Surgery) |
| Mark Howard, P.A. (Neurosurgery) | Courtney Watson, D.N.P. (Otolaryngology) |
| William Mallard, D.D.S. (Dentistry) | Derek Wilson, C.R.N.A. (Anesthesiology) |



Michelle, age 19, bone cancer survivor, with her mom

POST THIS END
1 foot (12 inches) from the floor.