

# Reflections from the **Foundation President**



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Perspective matters and ours views our work through the lens of the children and families we serve—as long as one child needs help, we will be there.

#### PHILIP SALERNO III

**CSH Foundation President & Chief Development Officer** 

Dear Friends,

Early in my career and before coming to Children's Specialized Hospital Foundation (CSHF), I remember leaving work early, extremely frustrated, after what I thought was a bad day. I stopped at my parents' house on the way home and my brother, who is 20 years younger than me, asked if I could take him to a baseball card show that weekend. In that moment, with that innocent question, my brother changed my perspective. He reminded me of what was truly important and I was able to let go of my frustration and relax. (In case you were wondering, I said yes.)

As I reflected on 2021, I realized that because CSHF is in the midst of the largest and possibly most important fundraising campaign in our history (Transforming Lives 2.0) it could have been so easy for us as an organization to lose perspective—to be blinded by the stress of hitting a goal and forget why we are doing it. But our team did not waiver. We stayed focused, remained true to our mission and values, and achieved our annual goals. We were able to keep things in perspective while faced with the pressure of an unprecedented campaign and tumultuous national and world events. I have never been prouder of our staff, trustees and volunteers.

We are pleased to share the results of our efforts in 2021, a year that, while not without challenges, brought significant success as we funded the expansion of multiple outpatient sites throughout the state, innovative research initiatives as well as vital hospital programs and services. We have never been more committed to our responsibility to ensure that the hospital's world-class pediatricians, nurses, and therapists have the resources needed to do their work and enhance the future for the growing population of children with special healthcare needs.

Perspective matters and ours views our work through the lens of the children and families we serve—as long as one child needs help, we will be there. I know that you share the same perspective, and I thank you from the bottom of my heart for helping us uphold our commitment to the thousands of children and families who rely on us to get through some of the hardest times in their lives. With sincere gratitude,



# 03: COVER STORY

#### **Colbie Knows No Limits**

Meet Colbie Durborow, the four-year-old firecracker who was born a micropreemie and defied all odds to become who she is today.

### **Transforming Lives 2.0**

capital campaign is in full swing and the largest in CSH Foundation history.

**Capital Campaign** initiatives, impact, and progress.

#### Tattiana Bazan

finds hope for her family when she discovers CSH.

2021 FINANCIALS, **IMPACT & DONORS** 

#### CHILDREN'S SPECIALIZED HOSPITAL FOUNDATION

# BOARD OF TRUSTEES



From personal experience, I know that the level of specialized pediatric care offered at Children's Specialized Hospital is unique to the state of New Jersey. Children with special healthcare needs, whether they are local residents or they come to us from other areas of the country, have access to a highly differentiated system of inpatient, outpatient and long term care facilities because of the CSH Foundation's directed, century-old commitment to kids and their needs.

As part of the Foundation's Board of Trustees, first as a trustee and now Chair, I've seen first-hand what a focused board and donors can achieve together. Reflecting on all that the Foundation accomplished in 2021, I'm grateful for such a dedicated board

and generous donors who support the transformational work we are doing to give so many children the possibility to thrive in an advanced and competitive world.

The progress that our Transforming Lives 2.0 capital campaign is making in expanding CSH into new communities plus important research in the areas of autism, brain injury, chronic illness, cognition and mobility ensure that thousands more children will now have the opportunity to live their best lives. On behalf of the entire CSH Foundation Board of Trustees, thank you for your commitment and your generosity. None of this would be possible without you.

Sincerely,

Leslie Logan Taylor, Chair

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Children's Specialized Hospital Foundation Board of Trustees

# 2021 CSH FOUNDATION BOARD OF TRUSTEES

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# **COLBIE KNOWS NO LIMITS**

BORN A FIGHTER, SHE'S BEATING THE ODDS EVERY DAY

n November 22, 2017, after entering premature labor, Amanda and Colin Durborow welcomed their twins, Colbie and Bennett, to the world. Born at just 23 weeks, the twins were considered micro-preemies, with Colbie weighing 1 pound, 2 ounces and Bennett weighing 1 pound, 4 ounces. The twins were immediately sent to the Neonatal Intensive Care Unit (NICU) at RWJBarnabas Health's Monmouth Medical Center, where tragically, Bennett died two days later. Colbie remained in the NICU fighting for her life. "She suffered a bilateral brain bleed," shares Amanda. "She had a grade 3, grade 4 bleed and she was diagnosed with hydrocephalus."

Hydrocephalus is the buildup of cerebrospinal fluid which places extra pressure on the brain causing brain damage. At two months old, Colbie had a Ventriculoperitoneal Programmable (VP) Shunt placed. This shunt is a device positioned in the back of Colbie's head that helps the fluid drain from Colbie's brain so pressure doesn't build. "Colbie has undergone a total of seven surgeries, six of which were brain surgeries. The girl's a champ," shares Amanda.

After 153 days in the NICU, Colbie was able to go home, but Amanda and her husband weren't sure what the future held for her little girl, "I remember the doctors telling us that they had no idea what Colbie's quality of life would be like. We just didn't know what to expect."

#### **Taking Control**

As a preemie, Colbie started with early intervention and outpatient physical therapy early on to stay on top of her development. After about two years of therapy, Amanda and her husband ultimately made the decision to switch to Children's Specialized Hospital (CSH), "I felt in my gut that we needed to make a move," says Amanda. "It was nerve wracking and I kept thinking, 'are we making the right choice?', but CSH came highly recommended from other NICU moms. We've been here for about a year now and we're thrilled with the decision!



After making the switch to CSH, Amanda and her husband received the official diagnosis that along with Hydrocephalus, Colbie also has Cerebral Palsy (CP), which affects her ability to move and maintain balance and posture. "We started noticing early on that Colbie was experiencing some delays and weakness in her legs and on her left side, so when we did get the CP diagnosis, it didn't come as a huge shock," shares Amanda.

An energetic three year old, Colbie comes for outpatient physical therapy at the CSH Toms River location, and sees physical therapist, Sarah Hatton. "Ms. Sarah is just so wonderful," beams Amanda. "She has become my go-to person, leading the pack in terms of Colbie's care team." Colbie loves coming to her physical therapy sessions with Sarah. "She loves Ms. Sarah, but I think she also loves the different equipment available to her that we don't have at home, like the big exercise balls that would probably take up my entire dining room," Amanda shares through laughter. "Colbie and I have accomplished so much together," shares Sarah Patton, PT, DPT at Children's Specialized Hospital. "I promised myself when I first began working with her, that I would never underestimate the power of what she is capable of, because she has beat the odds every step of the way. The odds just don't apply to Colbie. Her work ethic, drive, and positivity defy them every time!" Sarah shares that she and Colbie have worked hard to make use of her forearm crutches and to progress from her gait trainer. "We recently had a big moment of success together where she was able to take a long string of steps with her crutches without support for the first time! It was amazing to watch her shine and meet that goal." Sarah also shares that the best thing about Colbie is no matter the struggles she's taking on at any given time, she is ever kind, loving, and encouraging to everyone around her. "She faces hard obstacles every session and every day, but is always the first to tell you that YOU'RE doing great," says Sarah. "I just think she lights up the world around her."

Amanda says that Colbie also loves the atmosphere of the therapy gym, and how it's an open concept so there are other kids working on their own therapy goals at the same time. "I remember a few months ago my parents took Colbie to a session while I was at work. They told me that during the session, Ms. Sarah was helping Colbie practice walking and she told them Colbie's leg was looking good, so Colbie screamed across the gym to the other therapists and patients, 'Hey guys! My leg is looking good today!' Everyone laughed, but that's the support the kids feel at CSH! It's special."

#### **An Infectious Personality**

Sassy and sharp as a tack, Amanda says Colbie is a happy kid who doesn't slow down. "Colbie loves to just run and jump around with the neighborhood kids." She also walks with her walker alongside her great-grandmother, who also uses a walker. "When we went to visit my Nanny over the summer, she asked Colbie if she wanted to go for a walk. Colbie looked at her and said 'I sure do!' and they were off! Even more recently we were visiting and Colbie was using her crutches and loved that Nanny was using her cane, too. They have a special bond."



Amanda shares that Colbie loves the color green, plays pretend chef and loves going around taking everyone's ice cream orders. "In July she welcomed a baby sister which has been an amazing experience. Most of all, she just loves being around people."

# TRANSFORMING LIVES 2.0

# DESIGNING THE FUTURE OF PEDIATRIC CARE



n 2021, Children's Specialized Hospital (CSH) Foundation launched the largest capital campaign in our history. The \$45 million we aim to raise through the Transforming Lives 2.0 capital campaign will shape the future of pediatric care in New Jersey—and beyond—by expanding our infrastructure to reach to thousands more children and funding transformational research that will enhance the future.

Advancements in medical technology have made improvements to CSH's infrastructure imminent. CSH has been meeting the greatest needs of children for over 130 years and many of our older outpatient centers have reached or exceeded their optimal use as centers for excellence in pediatric specialized care. Upgrading technology in all of our facilities is equally important to improve the efficiency and quality of care each of our facilities delivers.

This historic campaign is led by a team of New Jersey superstars including Toms River resident and former Major League Baseball All-Star Todd Frazier and his wife, Jackie. Chairing the campaign are two long-standing members of the CSH Foundation Board of Trustees Mark Montenero, President of Autoland Toyota, Chrysler, Jeep, Dodge and Ram Trucks in Springfield, and Ed McKenna, Senior Partner at McKenna, Dupont, Stone and Washburne and former mayor of Red Bank.

Currently serving over 35,000 children each year, the infrastructure projects underway will allow us to care for 50,000 children annually by 2025. The results of this campaign will enhance our ongoing programs and medical services and break through barriers that restrict access to care for the children who need us most.

#### **Big Strides Toward a Bold Vision for Pediatric Care**

In 2021, we marked the first of many milestones in this campaign. The public phase of the campaign was announced in conjunction with the opening of the first of four new outpatient centers, the Kenneth Esdale Pavilion in Union, NJ on November 20. Campaign donors, foundation and hospital leadership, and local and state officials gathered for a reception and tour of the new state-of-the-art facility that was designed using input from members of CSH's family faculty and therapy staff. This new facility serves as the template for the remaining



three outpatient centers that will open over the course of 2022 and 2023.

Also in November, we announced our fundraising goal and the results of our work securing major gifts during the silent phase of the campaign that totaled just over \$31 million toward our \$45 million goal. These funds were raised over 18 months beginning in early summer 2020. This incredible milestone of raising \$31 million exceeds the full amount raised by CSH Foundation to fund the CSH inpatient hospital in New Brunswick in 2007 and it far exceeds any fundraising accomplishments of our 36-year history.

"All donors to this campaign are directly supporting our expansion into new communities so that more children will have access to the life-changing care provided within our walls," said Matthew B. McDonald III, MD, President and CEO, Children's Specialized Hospital.

When the campaign is complete in early 2023, we will open two more outpatient centers located in Toms River and Bayonne and the renovations will be complete on our Mountainside Long Term Care Hospital.

### MAJOR DONORS TO TRANSFORMING LIVES 2.0 (\$10,000+)

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Corporate Matching Gifts Received from Deloitte Services LP, Goldman Sachs Gives, Johnson & Johnson Consumer Products Company, Toyota Dealer Match Program, Merck Company Foundation & Novartis US Foundation Children's Specialized Hospital (CSH) has been responding to the greatest needs of children since 1891—growing from one hospital in Mountainside to 15 facilities across the state of New Jersey. This new era of expansion that we have embarked upon today is driven by the fact that there are 200,000 children in New Jersey alone who are in need of our services. In response, the Foundation launched the Transforming Lives 2.0 campaign to fund the expansion of hospital services into new areas to serve more children and incorporate the best technology available to give our patients the tools they need to reach their full potential.

#### **Expanding the CSH Footprint**

CSH Foundation is working in tandem with the hospital to fund a three-year strategic plan that will increase patient capacity by more than 30%. One hundred percent of every dollar raised in 2021 directly contributed to the hospital's expansion and innovation initiatives through the Transforming Lives 2.0 capital campaign.

#### **New Outpatient Centers**

The strategic plan includes opening four new outpatient centers that will expand our reach into new communities and combine some facilities to serve patients in existing communities better.

The first of these, the Kenneth Esdale Pavilion, a three-story, 66,000 square-foot outpatient center, opened its doors in **Union**, NJ in November 2021 and affords a 15% increase in patient capacity.

The first CSH outpatient center in Monmouth County will open this summer. Located in the Anne Vogel Family Care and Wellness Center in Eatontown, NJ, this new location expands access to a community of 250,000 children who live within driving distance.

A new CSH outpatient center in **Bayonne**, NJ will open in late 2022, providing the full array of outpatient services in an easily accessible location for more than 350,000 children living in the area.

The new Toms River CSH outpatient center has an estimated completion date of spring 2023 and will bring together the outpatient services currently offered at the two CSH Toms River sites to one convenient, state-of-the-art location to better serve our Ocean County patients.

Outside of the capital campaign initiatives, CSH further expanded access to the special needs pediatric community in NJ by taking over the St. Barnabas Medical Center's Pediatric Rehabilitation Services in West Orange, NJ.

Increasing Long Term Care Capacity in Mountainside In late 2021, renovations began on our flagship hospital in Mountainside, NJ to expand our Pediatric Long Term Care Center. Once completed, capacity will increase to house 62 medically fragile children. The hospital will also be updated with state-of-the-art medical technology to better care for those children in our care whose medical conditions are too complex to be properly cared for at home.

Pictured below from left at the new Kenneth Esdale Pavilion in Union, NJ: Dr. Matthew B. McDonald III CSH President and CEO, Mark Montenero CSH Foundation Board of Trustees, Leslie Taylor CSH Foundation Board of Trustees Chair, Jackie and Todd Frazier Transforming Lives 2.0 Capital Campaign Co-Chairs, Edward J. McKenna, Esq. CSH Foundation Board of Trustees, Philip Salerno III CSH Foundation President and CDO.



hildren's Specialized Hospital has always been guided by an ambitious vision of a world where all children can reach their full potential. While hospital and foundation leadership can be proud of the many miracles that have happened within our walls over the last century, we do not rest on the laurels of those accomplishments. Instead, we stand on the shoulders of those that came before us and imagine new ways to continue our legacy of excellence.

#### Improving Outcomes Through Discovery, **Innovation and Development**

CSH Foundation has long supported the Center for Discovery, Innovation and Development (CDID) at CSH. CDID's mission is to develop, innovate and discover solutions for the advancement of the lives of children with special healthcare needs and their families.

CDID focuses on improving the lives of children, adolescents and young adults with special healthcare needs, and their families, by transforming healthcare and creating disruptive positive change through the discovery, development, growth, and commercialization of innovative care, products, services, collaborations, and ideas.

#### **Caring for Children Goes Beyond Their Medical Needs**

CDID has been an integral part of CSH's initiative to uncover and address Social **Determinants of Health (SDOH)** in our patient population. SDOH are the conditions in which our patients live, work, play and access care. They are affected by the social structures, policies and economic systems in place in our

patients' communities. SDOH account for 80% of all health outcomes and when patients do not have access to the best resources, they can be a major cause of healthcare inequity.

CDID initiated a fully integrated screening program across all CSH sites to identify SDOH for patients and their families. By the end of 2021, 4,263 families were screened and those needing additional help were referred to appropriate services by their CSH healthcare provider. CDID is providing further impact by expanding screening and referrals to thousands more families who are challenged by food insecurity, housing, transportation, legal issues, among others. In an additional effort to improve patient outcomes, CDID partnered with the Community Food Bank of New

Jersey and began distributing packs of food to families who identify as food insecure at our Clifton and Newark outpatient centers. In 2021, 375 families were served by this program. Due to its success, there are plans to expand this program to additional sites in 2022.

#### **Investing in the Future of Pediatric Care**

As part of the Transforming Lives 2.0 capital campaign, CSH Foundation raised funds to support CDID research initiatives that will transform the future of pediatric care and thousands of lives in the process. One such initiative is the partnership with software company **ATENTIVmynd™** to co-develop an integrated behavioral operating system for delivery of treatment by pediatric clinicians. This partnership has the potential to improve function for millions of children globally who struggle



with attention-deficit/hyperactivity disorder (ADHD) to reduce or eliminate the need of medication.

Additionally, funds raised through Transforming Lives 2.0 support the five key areas of research at CSH including autism, brain injury, chronic illness, cognition and mobility.

Scan here or visit https://www.rwjbh.org/ childrens-specialized-hospital/ cdid/ to learn more about the projects CDID has underway.





Children's Specialized Hospital Leadership Team from Left: Lisa Knothe VP and Chief HR Officer, Charles Chianese VP and COO, Michael Dribbon VP and Chief Research Officer, Joseph Dobosh, Dr. Matthew McDonald President and CEO, Dr. Colin O'Reilly VP and Chief Medical Officer, Dr. Kelly Keefe Marcoux VP and Chief Nursing Officer.

This past year has been all about transformation. From changes in leadership to expansion of services and the launch of critical research studies, CSH is fully immersed in one of the most transformational times in our history—and our donors have been fueling the incredible speed at which we are making progress.

The Transforming Lives 2.0 campaign is the largest in our history and 2021 was another record-breaking year for fundraising. With the support of our generous community and the exciting changes happening at the hospital, CSH is poised to remain the preeminent provider of pediatric rehabilitation in the United States—offering the highest level of care for even more children in New Jersey while educating and inspiring others to enhance pediatric care worldwide. The CSH Foundation team has been growing and changing to meet the expectations of our donors, fund the needs of the hospital, and make sure the dollars we raise make the greatest impact for the children in our community. Throughout 2021, we continued to review and refine our work, focusing on efficiency, innovation, and sustainability.

#### New Leaders at CSH Will Design the Next Generation of Pediatric Specialized Care

The hospital welcomed changes in leadership in 2021, with three established and dedicated professionals taking top leadership positions at CSH. Their unique qualifications and commitment to enhancing the lives of *all* children are the perfect

combination to continue our legacy of excellence in pediatric care.

Matthew B. McDonald III, MD was appointed President and Chief Executive Officer at CSH in June, 2021. Dr. McDonald's professional mission is parallel to that of CSH—to improve the care delivered to all patients through access, innovation and partnerships. A leader at CSH since 2014, he has led many projects that serve to redefine and expand how medical professionals treat children with special healthcare needs. Dr. McDonald's leadership as President and CEO will serve to enhance and expand access to CSH's nationally recognized programs to more families in New Jersey and beyond.

Colin O'Reilly, DO, FAAP, FACOP, FCCP, was appointed Vice President and Chief Medical Officer at CSH. In his new role, Dr. O'Reilly supports the overall clinical vision of CSH and provides medical oversight, expertise and leadership to ensure the highest quality and most compassionate care for our patients and their families.

Kelly Keefe Marcoux, PhD, APN, CPNP-AC, PPCNP-BC, CCRN-K, was appointed Vice President of Patient Care Services and Chief Nursing Officer at CSH. Dr. Keefe Marcoux supports the provision of patient care services in the rehabilitation hospital, long term care units, ambulatory sites, and community programs. Additionally she oversees patient safety and nursing practice and standards throughout CSH.

# A MOTHER FINDS HOPE

#### CSH CHANGED EVERYTHING FOR TATTIANA'S FAMILY



fter being referred to Children's Specialized Hospital (CSH) for neurodevelopmental services for her three-year-old daughter, AnnaBella, Tattiana knew that she wanted all four of her children to be patients at CSH. The expert physicians at CSH diagnosed AnnaBella with autism spectrum disorder (ASD), mixed receptive-expressive language disorder, sensory disorder, anxiety, attention deficit hyperactivity disorder (ADHD) and a number of other developmental and behavioral concerns. She quickly began receiving speech and occupational therapy as well as psychology at our Mountainside and Warren outpatient centers.

Having concerns about all of her children's developmental progress that were dismissed by pediatricians seen in the past, Tattiana was so relieved to finally find somewhere to give her children the help they needed. Her mother's intuition proved to be right. Once Raziel, Leo and AnnMarie came to CSH for evaluations, they, too, received diagnoses of ASD and ADHD. Now Tattiana finally had answers and a strategy to help her children reach their full potential.

"My experience at Children's Specialized has been like no other," said Tattiana, "The therapists that have worked with my children have given it their all. When my kids received occupational therapy from Anna Nierenberg, we were able to learn more about each of their conditions as a family. I was taught different ways to help each of my children individually at home and during our daily routines."

What makes CSH different from other pediatric facilities is the focus on patient and family centered care, which means that each child receives a unique treatment plan involving the family in every decision and educating them throughout their child's journey. At CSH, Tattiana learned many different activities to implement at home such as dry brushing techniques to stimulate the nerve endings of the skin, generally serving to "wake up" the nervous system. Joint compressions provide the body with deep pressure proprioceptive input, adding a calming element to the nervous system. She was also taught to use a listening program for her kids that she still uses to this day. CSH gave the Bazan family critical tools to improve their daily lives such as learning to tolerate food textures and even "potty training"--which was a huge challenge before starting therapy at CSH.

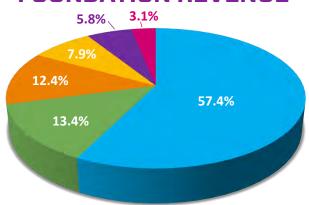
"Anna has been more than a therapist to my family," said Tattiana. "She has been like a friend that has helped to guide me and teach me things that I didn't understand my children needed help with before."

CSH initiates a lot of discussion and education around a child's diet, behavior, toileting frequency, schedule and set-x "I can't say enough nice things about this family! It is a pleasure to work with her and her children these past few years," said Occupational Therapist, Anna Nierenberg. "Tattiana is such a devoted mom who always goes above and beyond for her children. All of her children are a delight to work with in OT as they always try their best."

All of Tattiana's children are on their way to reaching their full potential. Before coming to CSH, none of her children liked the feeling of sand on their hands and now they all love to going to the lake in the summer as a family. AnnaBella enjoys horse-back riding and AnnMarie enjoys spending time with her friends and going to the mall like most teenagers her age. Raziel and Leo love swimming and hiking with the family bulldog, Hazel. The doctors and therapists at CSH listened to Tattiana's concerns as a parent, and it changed everything for her family.

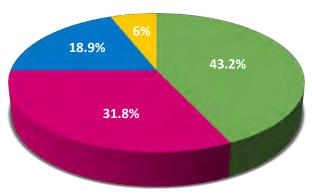
STATEMENT OF REVENUE AND GIFT DISTRIBUTION YEAR ENDING **DECEMBER 31, 2021** (IN THOUSANDS OF DOLLARS)

### **FOUNDATION REVENUE**



Capital Projects & Equipment	8,082
■ Children's Miracle Network	1,889
Annual Giving & Events	1,740
Grants	1,114
■ Investment Income	820
■ Planned Giving & Bequests	437

### **GIFT DESIGNATION**



- Capital Projects & Equipment
- Hospital Programs & Services
- Research & Innovation
- Hospital Benefit Fund



100% of every gift to Children's **Specialized Hospital Foundation** supports the hospital's greatest needs.

Fundraising revenue was not applied to operating expenses.

YOUR GIFTS MADE TRANSFORMATIONAL



CHILDREN SERVED

**NEW STATE-OF-THE-ART** OUTPATIENT CENTERS ADDED IN 2021





**NEW PEDIATRIC** 

IN THE AREAS OF AUTISM, BRAIN INJURY, CHRONIC ILLNESS, COGNITION AND MOBILITY

<u>GIVEN TO ASSIST WITH</u> MEDICAL BILLS THROUGH THE HOSPITAL BENEFIT FUND





SOCIAL DETERMINANTS OF HEALTH SCREENINGS

**FAMILIES** 

RECOGNIZED BY NEWSWEEK AS A SPECIALIZED HOSPITAL





**CHILDREN LIVING WITH AUTISM SPECTRUM DISORDER** RECEIVED EXPERT CARE

CHILDREN'S SPECIALIZED HOSPITAL IS NOW THE LARGEST REGIONAL PROVIDER OF AUTISM SERVICES

DEVELOPMENTAL

**PEDIATRICS PATIENTS** 



#### **Transformative (\$1,000,000+)**

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#### Visionary (\$500,000+)

Costco Wholesale Corp\* PSE&G Golf Outing to Benefit CSH Mr. Mark Montenero/Autuland\*\* Vincent Baricaua, RE/MAX Our Town\*\*

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