



DISCUSSION GUIDE

A RESOURCE GUIDE FOR THE PLAY
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**"We don't heal in
isolation, but in
community."**

-S. Kelley
Harrell

- Did this show make you rethink the way you view caregivers?
- Have you ever been in a situation where you wanted to fix something for someone you love but couldn't?
- How do you process grief and the fear of loss? Do you avoid it, confront it, or find ways to manage it?
- Do you have people you could turn to if you were struggling?
- What steps can you take to be more involved in your community?

THREE YEARS OF STRENGTH, LOVE, AND COMMUNITY: NICO'S JOURNEY

by Nico's Family

Nico is turning three in March, and his journey has been extraordinary. He has undergone seven surgeries—including heart surgery, cleft palate repair, and a G-tube placement—and has attended over 250 medical appointments. Most of his specialists are in Charlotte, 2.5 hours from home, and we've spent countless nights at the Ronald McDonald House, our dear home away from home. Since he was four months old, he has received in-home therapy multiple times per week, working with his physical, feeding, speech, and occupational therapists.

Our journey began before he was born. At our 20-week anatomy scan, we learned he had a non-functioning right kidney. A few weeks later, additional concerns arose—his spine, heart, and overall development needed further evaluation. Seeking the best care, we traveled to Boston Children's Hospital, where specialists confirmed he would likely need heart surgery at birth.

When Nico was born, he spent a month in the NICU at Levine Children's Hospital, where doctors checked him from head to toe. He had feeding difficulties and physical anomalies but was doing well enough to come home. A few weeks later, at a routine cardiology visit, we learned he indeed needed heart surgery, and we returned to Levine. The first year was a blur of hospital stays, medical appointments, and navigating healthcare and insurance. We secured resources, including a night nurse to help manage his G-tube and aspiration risks, giving us some rest and stability as new parents.



THREE YEARS OF STRENGTH, LOVE, AND COMMUNITY: NICO'S JOURNEY CONT.

by Nico's Family

At 7.5 months old, genetic testing finally gave us answers—Nico was diagnosed with Kabuki Syndrome, a rare genetic disorder affecting 1 in 32,000 babies. With this diagnosis came grief, gratitude, and a community—families worldwide who share similar challenges and victories. We also found a Kabuki Syndrome specialist, a neurogeneticist at Johns Hopkins Hospital, who now advises Nico's care remotely and sees him annually.

Now, as Nico turns three, he is transitioning from early intervention therapy to school-based services. He will soon undergo evaluations for his Individualized Educational Plan (IEP) and begin preschool. We are excited and nervous as he steps into more independence.

This Spring, Nico will also take on a new role—big brother! He is the light of our lives, and there is no one I admire more. His resilience, joy, and open-hearted love inspire us daily. Other people also seem very drawn to his laughter and engaging enthusiasm.

Being a SEND (Special Education Needs and Disability) mom has changed how I see the world. I advocate differently, relate to others differently, and find beauty in every “inchstone” to milestone. This journey has been challenging, but it is ours, and I wouldn't trade it for another.

We are deeply grateful for our family, friends, and the Kabuki Syndrome community, and shared love, celebration, and belief in Nico's incredible future.



Additional Resources To Watch

SPEECHLESS

<https://www.imdb.com/title/tt5592146/>

THE INTOUCHABLES

<https://www.imdb.com/title/tt1675434/>

MIRACLES FROM HEAVEN

<https://www.imdb.com/title/tt4257926/>

PATRICE: THE MOVIE

<https://www.imdb.com/title/tt30342963/>

Book Corner

THE STILL POINT OF THE TURNING WORLD

BY EMILY RAPP BLACK

<https://tinyurl.com/bdekwhwb>

EMOTIONAL LABOR: THE INVISIBLE WORK SHAPING OUR LIVES AND HOW TO CLAIM OUR POWER

BY ROSE HACKMAN

<https://tinyurl.com/yrka9txx>

THE REVISED FUNDAMENTALS OF CAREGIVING

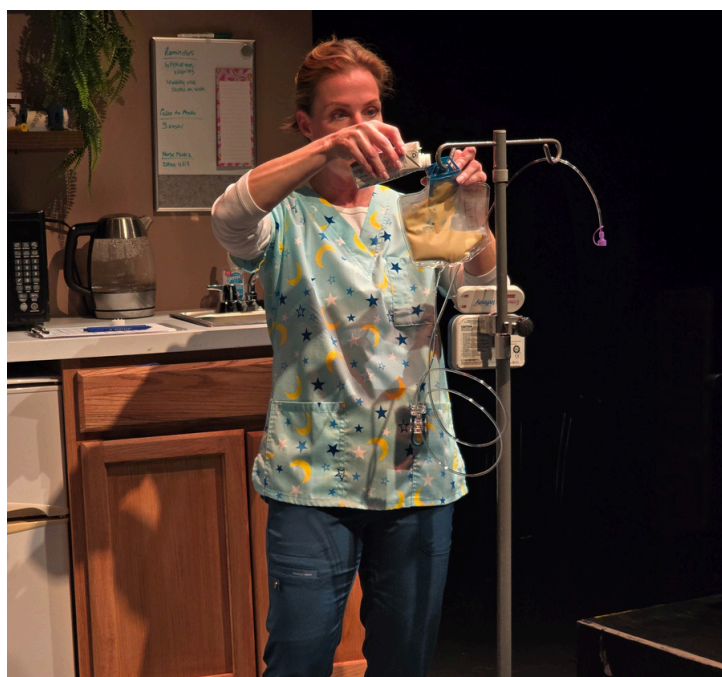
BY JONATHAN EVISON

<https://tinyurl.com/8xbprh2x>

THE LONELY HEARTS BOOK CLUB

BY LUCY GILMORE

<https://tinyurl.com/996btk7j>



Move the Mission Forward

Our mission is to create a performing arts experience that is socially engaged, professionally managed, and creatively inspired.

Now that we've introduced you to Mary Jane, we encourage you to join us in fostering meaningful conversations within your family and your community. Share your reflections on the play's themes, engage with others to deepen your understanding, and consider how you can contribute to creating a more inclusive and empathetic society.