



Case Manager Fallon Carnes examines the Unmasking Brain Injury exhibit of Kentucky that was on display at Cardinal Hill Rehabilitation Hospital this fall.

The colorful masks displayed at Cardinal Hill Rehabilitation Hospital in Lexington, Kentucky, are as different as the people who designed them. However, they all have one thing in common – they were created by brain injury survivors.

The traveling exhibit in Kentucky was on display at Cardinal Hill this fall and is part of the national project, Unmasking Brain Injury. Started at Hinds' Feet Farm in North Carolina, a special home for brain injury survivors, Unmasking Brain Injury began as a way for survivors to express themselves. They are given a blank cardboard mask and an array of art supplies to decorate it. The completed work includes a brief description, explaining the meaning behind the mask.

For one brain injury survivor, the color yellow on her mask represents the seizures she has at night, and copper is used to describe "the sadness I feel when this happens." Another swirls grays and whites to show the grief of losing his old self along with the "acceptance of the new me."

"It's really incredibly moving," said Michelle Graybeal, director of case management at Cardinal Hill. "If you read all the descriptions ... It's such a unique way to look at how it's affecting them."

The Kentucky display has 32 masks created by brain injury survivors from all over the state, including some Cardinal Hill patients.

Michelle, a board member of the Brain Injury Alliance of Kentucky, said in addition to serving as a creative outlet for these survivors, it's also helping educate the community on the prevalence of brain injury, as well as the impact it has on its survivors, added Tonia Wells.

Tonia is the brain injury program director for the Kentucky Department of Aging and Independent Living. She heard about Unmasking Brain Injury at a national convention earlier this year.

# UNMASKED

A NATIONAL PROJECT IS HELPING BRAIN INJURY SURVIVORS EXPRESS WHAT IT'S LIKE TO LIVE WITH THEIR CONDITION.

BY LAURA MCALISTER / PHOTOS BY ZAC MORRIS



“Brain injury really is a huge epidemic in our society,” Tonia said. “It’s a silent epidemic, and that’s where we hope this can help.”

Being a former case manager at Cardinal Hill, Tonia said it was one of the first hospitals she contacted about participating. Michelle along with Monica Davis, the therapy team leader for the inpatient brain injury and stroke units at the hospital, quickly agreed.

The state’s brain injury program provided the masks, and the hospital provided the art supplies.

“We probably turned in about eight to 10 masks,” Monica said. “The physical therapists, speech and occupational therapists were all involved. We went to the gym, and they painted, and we talked about the masks. Some had a little anger, and some felt their bodies were different now. This was just a good way to express those emotions and feelings. The patients loved it.”

So have the many who have viewed the masks since Hinds’ Feet Farm started the project last year. Now more than 20 states are participating in Unmasking Brain Injury, with a website displaying the many masks and their stories and several traveling exhibits, such as the one in Kentucky. After its display at Cardinal Hill, the exhibit is headed to a hospital in Louisville.

Michelle said Unmasking Brain Injury is also being used to help lobby for legislation to prevent brain injuries, such as a bike helmet law now under consideration in Kentucky, as well as funding for brain injury survivor programs.

She also hopes the colorful masks and stories behind them will spread awareness to this all-too common condition and the impact it has on its survivors.

“This is giving people, not just politicians, an idea of how many survivors there are out there,” she said. “There may be one sitting next to you, and you wouldn’t know it. A lot suffer in silence. The thing that really strikes me is that these really get to the heart of who that person is.”

**The survivors’ masks are only identified by their first name to protect their privacy. The following are a sampling of masks and their descriptions in the survivors’ words from the Kentucky exhibit.**



## CLOCKWORK ORANGE

**Name:** Shannon

**Brain Injury:** Stroke while being treated for leukemia

**Explanation of Mask:** I have my days that aren’t so good but most of the time it’s pretty positive. I wanted my mask to show that there is light at the end of the tunnel. I have been given lots of support and worked with many good medical professionals.

Stroke – It’s small because I didn’t want it to be the focus.

Clock – Represents my memory of getting shots at the same time every day and I also have difficulty with managing my time now. I lose track of it.

Lipstick – Represents always being me. At the time of my initial treatments I had lost most of my independence but it was still a little bit of me.

Light orange color, orange ribbon and eye patch – Presence of leukemia. I was faced with losing my eye or losing my life. I realized how important it is to be alive!

Boxing gloves – The fight.

Ruler – Tools I have been given at rehab.

## BRAIN ON FIRE

**Name:** Phylicia

**Brain Injury:** Severe traumatic brain injury (including expressive receptive aphasia) secondary to motor vehicle accident

**Explanation of Mask:** I remember my first day at intensive outpatient rehab and thought mentally I was fine. Then a few days passed and I met my psychologist there and she asked me something about my college and I couldn’t remember and I started crying. I realized something was wrong. Denial is a big part of it because you don’t want to be in this situation. A lot was just having to realize there was a point and a purpose to be at rehab. I felt at first like I didn’t belong but now I know we are all going through the same thing no matter what level we are on.

Red/Fire – Represents my anger, what I have felt the most, especially at the beginning. Fire brings together many different emotions (colors).

Blue – Mixed emotions, denial, strength, clarity, loyalty

Fist – Strength

Kellan – My son has been my motivation.

Purple, eyes with heart tear – Sadness and pain related to losing my sight in my left eye, but I am beginning to accept it.



## OUT OF THE BLUE

**Name:** Ashley

**Brain Injury:** Post concussive syndrome secondary to motor vehicle accident while working in the back of an ambulance as a paramedic

**Explanation of Mask:** The blue is the EMS color because I got hurt while working as a paramedic and my work was a lot of my life. Blue is also a calming color. One eye is closed and one eye is open to represent the anger and sadness I tried to keep inside but I can now see things getting better and I am letting go of anger. The string represents how I used to not talk to anyone about my injury, trying to keep it hidden as well as possible. Safety pins represent my opening up and beginning to share.







## TAKING NOTE

**Name:** Carin

**Brain Injury:** Stroke

**Explanation of Mask:** Green eye shadow, blush and lipstick—I wore my makeup throughout my rehab. It was always important to me because it represents how “I am still me.”

Blue—Represents losses. I am currently not able to volunteer or drive. I was very active before the stroke.

Red—Things I am thankful for.

Yellow—My progress and hope.

The hardest part for me is the loss of independence. I’m used to helping others, from my career and my volunteer jobs. Not ME asking for help.



## FAITH AND FAMILY

**Name:** Doug

**Brain Injury:** Anoxic encephalopathy following an infection and cardiac arrest

**Explanation of Mask:** This experience speaks to being aware of your body and not hesitating to get yourself looked at if something is out of sorts. If I had hesitated I might have been worse or might have died. It was luck to make the decisions to go and get there in time. I got really, really lucky both times I had medical problems.

As much as people complain about the health-care system, I couldn’t have been in better hands. I couldn’t have been with more professional, nicer people. I gave some people a really hard time because I was out of sorts. The healthcare system worked for me. The personal interest people take is impressive; it means the world to feel how genuine they care. I feel very lucky, so blessed.

Heart—My heart was central to my health challenges and represents the love shown to me by family and friends.

Soccer ball—Love of the game that my son and I share.

Red hair—Two most important people in my life, my wife and daughter, nothing but trouble.

Cross—My faith pulled me through.

Names of my dogs and cats—the family zoo, couldn’t live without them.

Blue—feeling blue, now blue skies ahead.

## LETTING GO

**Name:** Janie P.

**Brain Injury:** Stroke, seizures

**Explanation of Mask:** I think the stroke allowed me to let some things go. I think I’ve let go of the negative things in my life because there’s no reason to hold on to it; it’s not going to help you get better. I have gratitude I may not have had otherwise. I’m finding new ways to express myself to communicate. I have had discoveries about myself. I think I’m a better person, but I’ve changed. Sometimes I feel like I’m not different and then I realize again I am.

Missing part of head—I look the same and my brain remains altered, wounded, but still mine.

Arrow—My stroke was in my right hemisphere but affected the left side of my body. That was the path of the alteration of my brain.

Mechanical gears—The workings of my mind have changed. I don’t have a reference for time. I remember some things really, really well and other things I can’t. It’s hard for me to stay organized and on task. I get anxious.

Earring and black eyeliner—I’m not able to get both my earrings in or wear my makeup because it’s hard to do. It’s liberating though. Now I’ll go to the makeup counter at the mall if I need to get dressed up.

Right eye—I felt like my eyes were full of glass when I had previous TIAs. I may have minimized warning signs.

Left eye—My visual processing has changed but I see HOPE. I look forward to see how much more of me there will be.



## ANGELS AND DEMONS

**Name:** Paul

**Injury:** Fall related to substance abuse

**Explanation of Mask:** Black—represents being thrown into a dark place without the understanding of where I was until I got into treatment at rehab and learned about the brain and myself.

Angel—My guardian angel who is my mother; I believe she saved me from the clutches of death and has continued to watch over me.

Devil—Represents all the evil things that were happening before and after my injury; drugs, anger, stress, depression, etc.

XXs on my nose—Represents my loss of smell.

Tears—Represents all the crying I have done and my loss of emotional control since my injury.

Frown—My sadness and not understanding.



## STANDING STRONG

**Name:** Steven

**Brain Injury:** Motor vehicle accident

**Explanation of Mask:** The mask I made to explain what I feel like. I'm not the only one in the world who has a brain injury. There are a lot of people in the world who have the same brain injury. I don't get down and I'll always think positive. Nothing will ever get me down.

*(From the cover)*



## A SECOND CHANCE

**Name:** Mark

**Brain Injury:** Motor vehicle accident

**Explanation of Mask:** Grief from loss of ones-self. Acceptance of the new me. Easy words to say but very difficult and painful. Finding the new me I found to be a surprising discovery re-inventing myself. Like this mask very dark and gray world of pain and confusion to a clean blank canvas; my second chance. Art has helped me heal talents uncovered. A life renewed. **H**

## Make the Masks

For more information on Unmasking Brain Injury and how to take part in it, visit [unmaskingbraininjury.org](http://unmaskingbraininjury.org) and fill out the form to receive a packet with guidelines on facilitating the program and suggested materials.

