



Former Redskins Quarterback  
Mark Brunell

## The Children's Inn at NIH

# A Warm Welcome

By RYAN STAYTON

Imagine your child is sick with a rare disease, doctors are trying new experimental treatments to help him or her get healthy. Your days are trying and emotional, at night you curl up in the hospital room or go home for much needed rest.



*Cape Goalie Olie Kolzig at Childrens Inn at NIH*



*Former Redskins Quarterback Mark Brunell visits with children at NIH*

pediatrician or a local hospital after those conventional treatments have failed. Due to the rare nature of their afflictions, most children travel a great distance for their treatment.

In some cases, children aren't admitted as a last resort. The NIH, also, routinely conducts studies (the NIH is now working on their first comprehensive study of autism) on new conditions in which they invite as many as 300 kids with the studied condition. The studies are helpful because they allow families ample time to plan their visit and The Inn has time to train their staff on how to best interact and support anticipated children.

Next door to the NIH is The Children's Inn ([www.childrensinn.org](http://www.childrensinn.org)), which is a welcoming environment, filled with supportive staff and many families in similar situations. "There are so many things these parents take care of on a good day," Kathy clarifies, "and when you have a sick child you just need your community to help, and so our job is to

rebuild their community for them and play that part and navigate the process." The NIH nurtures their patients as well as family not only through service but convenience, as well.

There are no charges; families are welcome to stay as long as needed without paying the extra expenses. Dr. Philip Pizzo, the former pediatrics chief of the National Cancer Institute in the 1980s, is much to thank. After witnessing many families forced to loiter in the waiting room without a comfortable alternative, he enlisted the help of several congressional spouses

and families to pursue building The Children's Inn. With donations from the NIH (who donated two acres); \$3.7 million from Merck & Co., Inc. and the bountiful efforts of thousands of other charitable citizens/corporations, "The Inn" is liberating. The Children's Inn opened its doors to welcome NIH patients and their families in June 1990. After already housing families from all 50 states and 74 countries worldwide, The Children's Inn has made matters a lot



*One of the many play areas at The Childrens Inn*

more encouraging for patients and parents.

The Children's Inn accomplishes many goals. It gives residents and families home-like surroundings, where they can live both comfortably and close to NIH. Founding board member and current Inn CEO Kathy Russell describes, "The second goal is to offer psychological and emotional support for families and to heal the spirit of these kids and their siblings." They're incredibly successful at accomplishing this, but as you can imagine it's no small task.

Individuals ranging from age three days old to 26 years old are welcome at the NIH; however, they must be treated at the NIH (which requires an approval or referral) in order to book a room with "The Inn". If a child is diagnosed with a rare cancer," Kathy explains, "and their doctor calls the NIH saying they think the child would qualify, then if they're approved the process starts and we'll get a call from a social worker saying they'll arrive tomorrow."

Ranging from an expansive 72,000 square feet, there are 59 private rooms (In 2001, 22 rooms were added and leisure space was added). There are plenty of skylights and windows tucked amidst the woods. Its centerpiece is the common living areas, where families and patients can relax; more importantly, where they can meet other families in similar situations. NIH is everything from comfort to support.

When walking through the front door, you walk into an open atrium stretching two-stories high. Centering the atrium is a remarkable stone fireplace that remains lit in efforts to reassure families while sitting in

*Photography by Randy Sager*



*Sports Ambassador Alana Beard of the Washington Mystics*

the room. "The space is designed to bring families together" says Kathy. Once families arrive, they quickly see that "The Inn" isn't just functional, it's fantastic.

"Everything we do is driven by family's feedback," Kathy explains. "When we opened, the families who first participated said it's important for them to be able to communicate together, so they wanted TVs in communal spaces instead of in their rooms." Helping to lift one's spirits, there is: a game room, computer lab, library, a teen lounge with a pool table, video arcade and a big-screen TV with movies. Cancer survivor, Lance Armstrong donated an exercise room equipped with cardiac and weight-lifting equipment. For parents, a business center is available with wireless internet; small lounges and a butterfly garden. "The Inn" was recently renovated to include a meditation room.

There are daily activities and events for



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the entire family, such as: bingo, parties, puppet and magic shows. “The Inn” includes a Giggles Theater, which hosts frequent music and comedy performers. “The kids aren’t poked and prodded here, and we want them to cease being patients so they can just be kids again.” Among these events, field trips, attending sporting events and other special events are scheduled. “We want The Inn to be a different experience from that of a hospital,”

Their Spiritual Wellness Program has a chaplain on staff for support. “We like having that available when our families return home to The Inn,” Kathy continues, “and we host such culturally and religiously diverse groups that cultural, religious and political differences are left at the door making for a very supportive environment.”

They’re so in tune with making their residents feel at home that one thing children shouldn’t expect (unless necessary) is reprieve from school work. The Inn offers tutors to youngsters and coordinates with the NIH Children’s School to help keep current with schoolwork. A long-term goal is for an Inn education coordinator to work with a child’s home school and offer live video-conferences with teachers and classmates back home.

Jillian Bante was diagnosed with lupus, an autoimmune disorder, at age 11. She lives in Michigan and was one hour away from the nearest hospital (one that had never treated a child with a similar disease). When those treatments weren’t working, her family looked for alternatives and found an experimental stem cell transplant being practiced at the NIH. “We went there as a last resort,” Jillian explains, “it was like a magic place with everything I’d need or want. We saw ten doctors every morning and there was no wait,” said Bante, who lost her sight because of the disease and is still legally blind. “The people there are extraordinary and they connected with me on a different level. It’s a one of a kind place and I was lucky to be able to participate.”

Almost three years later, she’s now in remission and only has to go back to “The Inn” every six weeks for checkups, but she’s still involved with “The Inn”, experiencing it in a whole new light as a volunteer, from throwing pizza parties to donating time and money as an endeavor of thanks to “The Inn” for the continual venture. She has incorporated much volunteer work for the facility and hopes to inspire others to do the same.

There are two primary ways you can help

this profound facility: volunteering or through donation. “People get confused and think we’re federally supported because of our affiliation with the NIH,” Kathy says, “and we get some in kind support from them but we do have to do our own fundraising.” Working alongside their 28 employees they have 250 regular volunteers without whom “The Inn” couldn’t function. “I’m biased, but I’d say they’re the spirit of The Inn,” The Inn’s Director of Volunteers and Community Outreach Laura King says. “We have a waitlist of a couple years for volunteers and are very blessed, but we don’t want to turn people away.” The Inn’s volunteers are able to earn a U.S. President’s Volunteer Service Award every year.

The donation fundraising raises most of their \$5 million annual budget, half of which comes from their yearly congressional gala, AFCEA gala (Armed Forces, Communications, Electronics

Association), which draws the IT and business community to support “The Inn” and their “INNvitational” (golfing event). The remainder is beating the pavement by having bake sales to find donors (donations can also be made online, by mail or by fax, and churches and groups often fix The Inn’s Sunday dinners).

One new initiative, the \$93-a-Night Sports Ambassador Campaign, features six professional athletes helping to raise both the profile and donations for The Inn. Mark

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“The \$93 amount is how much it costs one family to stay for one night,” Kathy explains. Some of this money is put aside in an emergency fund that is used to fly in all family members (since parents often are forced to divide their time between home and hospital). Among other things, the emergency fund also pays for a family’s mortgage, helps with funeral costs and aids for hurricane victims staying at “The Inn”. “This is one way the community can support families in crisis and invest in the future of our children,” Kathy says. “It helps us keep families together during the largest crisis they will ever face.”

*The Children’s Inn...  
keeping kids and parents together.*