



Erin Hoecke and Kayleigh Boyd, representing the Canadian Rett Syndrome Association are rolled onto the Riders' football field by their mothers.

Kayleigh helps kick off campaign

by Michelle Valiquet
Press News Editor

OTTAWA — Kayleigh Boyd was a little smaller than some of the other football players who took to the field Sunday at Lansdowne Park, but she matched their determination and spirit.

The three-year-old South Mountain girl who suffers from Rett Syndrome, a neurological disorder which only occurs in girls, was taking part in the Canadian Rett Syndrome Association's national fundraising event — a ceremonial kick-off at centrefield.

Kayleigh along with 12 Ottawa female media personalities, including Rough Riders' general manager Joanne Polak, CHEZ 106's Shelly Hartman and CJOH's Carolann Meehann, joined two Rough Rider players in a pre-game kick-off to raise awareness of the debilitating disorder.

"We invited the female media to participate," explained Terry Boyd, Kayleigh's mother, in an interview before

the event, "because it ties in with Rett's striking only girls."

Kayleigh began her life, as many Rett girls do, as a typical child for her first 18 months, climbing stairs and beginning to say a few words before she started to regress just prior to her second birthday.

She rapidly lost her motor and cognitive skills and began to have screaming and laughing fits.

Terry said she had never heard of Rett Syndrome before Kayleigh was diagnosed with the disorder several months later and it's the low profile of Rett Syndrome which she and other Rett mothers want to alleviate with their awareness campaign.

MISDIAGNOSED

"We get new parents calling the association every week," said Terry, "saying their child has just been diagnosed as having Rett Syndrome. Many are older girls who have been misdiagnosed for years."

In Canada, Dr. Patrick MacLeod, a

medical geneticist at Queen's University, is currently heading research into the cause of Rett Syndrome. He maintains it could be the single most common cause of severe mental retardation in girls. In Europe doctors estimate the prevalence among severely and profoundly retarded females may actually be as high as 25 per cent.

Geneticists conducting research on the disorder say that a large proportion of girls diagnosed as "autistic" may in fact be suffering from Rett Syndrome, hence the need for further study and public awareness even amongst the medical profession.

Rett girls typically appear normal for the first six to 18 months and then begin a rapid deterioration in communication, social development and motor skills.

They may also experience repetitive behaviours such as hand washing, grinding teeth or facial grimacing, and increasing spasticity with age including epileptic seizures.

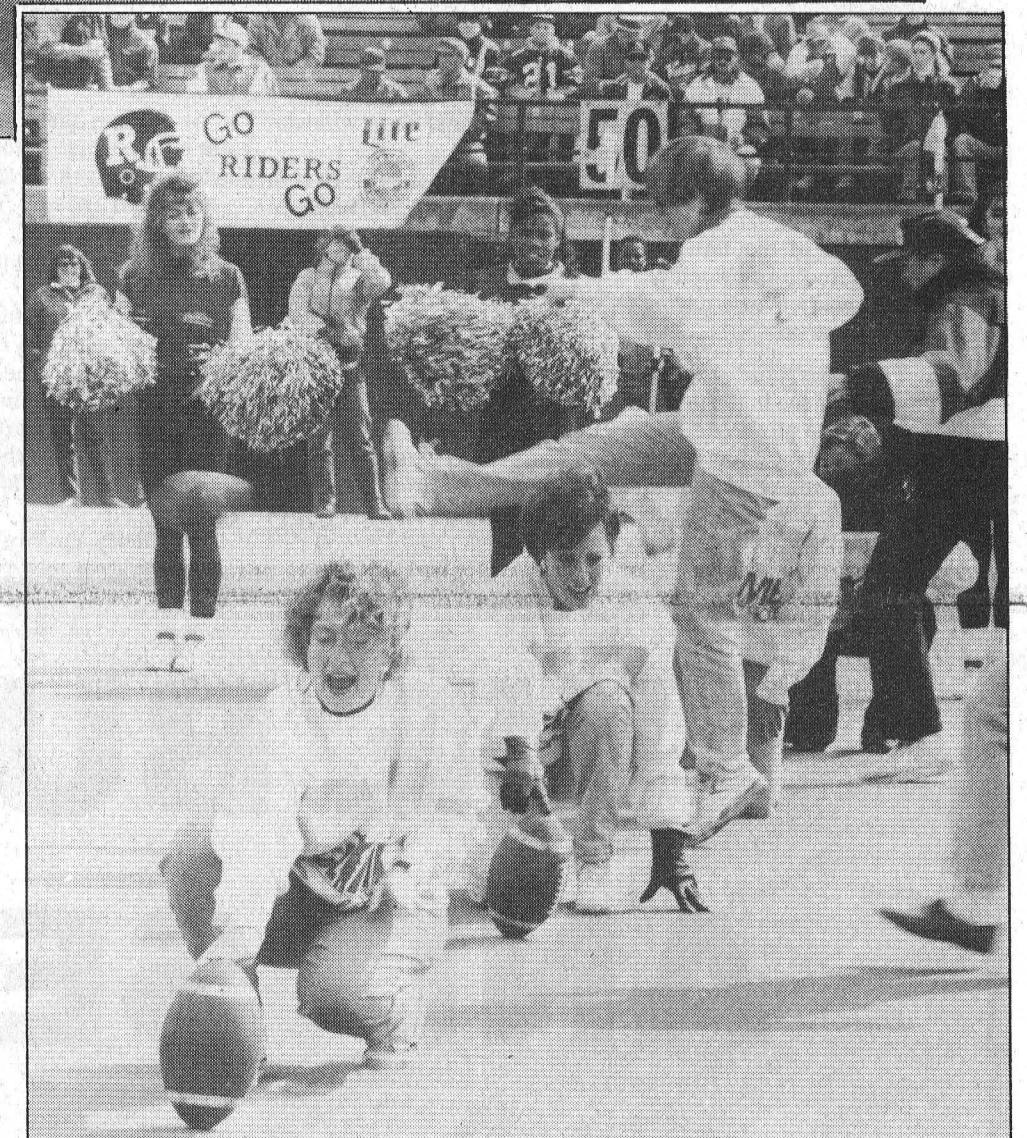
The Rough Riders organization also donated 150 tickets to the Rett Association for Sunday's Ottawa/Toronto matchup.

"When we approached the Rough Riders for help with our fundraising we were overwhelmed by their attitude. Joanne said what can I do for you?" said Terry.

Sunday's kick-off is not the end of the support given by these high-profile women. The majority of the 12 participants have also agreed to become honorary members of the association, lending their support to other fundraising events, she revealed.

Other upcoming events planned by the Rett Association include a volleyball tournament, LOEB barbecues and hot air balloon rides. The group is also presently involved in "Climb for Hope", a Mount Everest expedition by Canadian climbers.

Anyone wishing to volunteer time or make a donation to the Canadian Rett Syndrome Association can contact Terry Boyd at 989-2851.



The big kick-off takes off.



Kayleigh, 3, and Erin, 6, share a moment during Sunday's football game following the kick-off.
Press Photos—Valiquet

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Rett awareness climbs to new heights

by Michelle Valiquet
Press News Editor

SOUTH MOUNTAIN — As the latest ascent of Mount Everest, Canadian Rett Syndrome Association's Climb for Hope, winds down on the snow-swept hills of Nepal, Terry Boyd is hoping the reason for the expedition won't be forgotten once the climbers pack up and leave the mountain.

Boyd, whose three-year-old daughter Kayleigh suffers from Rett Syndrome, a neurological disorder which affects only girls, is the director of the association's Ottawa-region office.

Although fundraising for the 15-member, all-Canadian climb has been slow, the South Mountain woman is still satisfied with the event's success.

"Our number-one goal with Climb for Hope was to educate the public and health care professionals. Then we want to reach as many Rett families to inform them about the disorder. Fundraising came third," she explained.

A portion of the money raised will go towards an association project to build a data base of names of families with Rett girls, and doctors and therapists who deal with the disorder, providing a much-needed network of information.

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TREATMENT

No clear-cut genetic explanation for the syndrome has been determined to date, however, speculation is the disorder is carried on the same chromosome as Duchenne Muscular Dystrophy, said Boyd. Scientists hope by discovering the Rett gene they may unlock the secret of a treatment or cure.

"Twenty Rett families have blood ready and frozen in Montreal waiting to begin the testing to find the gene which carries Rett Syndrome. The scientists are assembled. All we need is the money to fund the research," she said.

The association is also gathering statistics about individual Rett girls.

"All the present statistics on the disorder are 20 years old. We need more current facts to develop better therapy. Some

success has been reported through the use of drugs in other countries but, without research, they can't be approved in Canada," said Boyd.

Although money raised through the Climb for Hope has been far short of the \$3-million goal, Boyd is optimistic that when the climbers return to Canada with photographs and stories more funds can be generated as well as public awareness of Rett Syndrome.

B.C. resident and expedition leader Dr. Peter Austen began organizing the climb in 1987. Over \$400,000 has been collected for climb expenses, with climbers each contributing \$7,500.

POSTERS

The association spent \$70,000 in printing posters distributed to schools across Canada which allow students to become involved in fitness, environment and nutrition activities that mimic the Mount Everest Climb for Hope.

The Climb for Hope is a record breaker for several reasons, including the fact it's the first time the Chinese government has allowed an ascent for charity. It's also the first time a French Canadian has been part of a Canadian expedition up the mountain. French Canadians have been part of other countries' climbs, but

never on one led by their native land.

And the climbers are carrying, besides a Rett-saurus, the association's mascot, a small satellite dish allowing them to transmit broadcasts to the outside world as they advance on the summit.

Some bad luck has plagued the climbers from the onset. The whole team was taken ill from contaminated water at their base camp as they prepared to start their ascent of the 8,848-meter summit (29,028 feet) and one climber even had to return home.

A few days into the climb, at the 7,800-meter mark (20,000 feet), just 900 meters short of the top, the Canadians lost a second climber, Tim Rippel, when he was injured in a fall. Yaks had to be sent up the mountain to take him back to base camp.

"The climbers are so committed to this project," said Boyd. "Tim said I don't know where the pain is more, in my heart because I have to turn back or my knee which was injured."

Boyd and other association members are available to talk to schools, health care professionals and service clubs about Rett Syndrome. Anyone wishing to order Climb for Hope sweatshirts can contact Terry Boyd at 989-2851.