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Lifestyle

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## MARVIN'S MISSION

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By René Hill

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Fighting spirit: Nine-year-old Mihdi Joon Brock, has been struggling since birth to beat a rare illness.

There is never enough time in the day for Marvin Brock.

The hours fly past as the Bermudian father of a young boy suffering from the rare disorder progressive kyphoscoliosis, which causes growth problems and a curvature of the spine, struggles to care for his nine-year-old son Mihdi.

But the endless struggle is the only way Marvin can imagine living – because his son is the focus of all that is beautiful in his life – “his mission”. Studies have shown that children with Mihdi’s condition often do not live to see the age of 12 but average life expectancy is 20.

To beat these statistics, Mr. Brock has already travelled the world in search of a treatment that did not require his son to be operated on every six months. What he found was an Oriental medicine doctor, Baolin Wu, who practices in California.

So Mr. Brock packed up his family and moved to California to facilitate Mihdi’s treatment, which is said to have improved his condition immensely, but which requires a daily regime of doctor’s visits, acupuncture treatments, physical and herbal therapies.

Mr. Brock, who is divorced from his son’s mother, established the Mihdi Joon Fund in Bermuda in 2000 to help raise the funds necessary for the little boy’s ongoing care, treatment and support. Recently, he has launched a fresh appeal for funding as he finds himself overwhelmed by the daily struggles of keeping his small family alive.

Mihdi’s physical fight for life costs upwards of \$80,000 per year and traditional treatments can have many side effects.

“He weighs only 43 pounds and is only 44 inches tall and the numerous conditions he is dealing with are more than likely too much for his slight little being to handle in a quick fix mode,” said his father.

“Some doctors feel that a treatment plan to insert shunts into his brain to drain excess fluid into his abdomen, and rods along his spine alone might be more than his repaired heart could handle.”

Mihdi and his father have chosen a different route.

“We have elected to address the whole person with Asian medicine,” Mr. Brock said. “This is a time consuming, slow, daily, little-at-a-time approach to resolve these challenges that he faces.”

“What it requires is my time and time for me is so precious as I have to do all the things that come with living and running a home – cooking, cleaning, driving to and from schools, Tae Kwon Do, swim class, not to mention grocery shopping etc.”

Mr. Brock must also perform numerous physical tasks, regularly throughout the day.

“In addition, I’m his therapist and have to lift him up by his head every ten minutes and, at times, every five minutes when he isn’t in school or on the doctor’s table,” he said.

“This makes holding a normal out-of-the-home job next to impossible.”

Many things have started to fall away he said – including Mihdi’s educational development and the time Mr. Brock needs to attend to the Mihdi Joon fund, in order to keep funds flowing in.

“The Fund requires a great deal of that time for research, writing, printing, stuffing letters for the fundraising in Bermuda and all the other things that come with finding ways to get funds in so that this mission can stay on track,” he said. But funds have been short and recently Mr. Brock even had to sell his computer in order to cover costs.

Meanwhile, the time squeeze is unrelenting.

“It then winds up that some therapy goes undone, and I’m not able to read to him and attend to his schooling as much as he needs,” admitted the stressed out father.

“I try to do this at night when he goes to bed, but I fall off to sleep with him before having read for 15 minutes or less. Now his fourth grade teacher says that unless I reinforce the work he does in school during day on the same night, he will not progress as he needs.

“Then his doctor says that he can tell I haven’t been disciplined about adhering to his prescribed therapy programme to date, but from now until Mihdi is 16 or 17, it is critical to not miss or waiver in holding him up every ten minutes, doing his parallel bar therapy every 15 minutes, his exercises and crawling twice a day.”

Mr. Brock sees these failures as his own and is pleased to report that Mihdi is still making progress in some areas.

“Nonetheless, in spite of my failure to stick to his daily schedule as outlined, he has come a long way.

Unfortunately, this is not as far as he could or should have been because there is no money to hire the help needed and not enough time to do all the things to sustain life and the mission.

“It is a Catch-22 situation actually – surgery and possible death, if not restricted movements and other complications, or the approach we are taking, which is almost, if not more, than one person can do in a day.

“The last ten years have been a long journey, and as we look forward, we are almost at the halfway mark as far as his treatments are concerned. The increased demands from Mihdi’s growth and development are bringing about increasing changes and the intensifying of his therapy schedule.”

He continued: “As a result, the last year has been extremely taxing on many fronts. If it were not for the kind and generous contributions from a particular Bermudian donor, I have no idea where we would be in this mission.

“The unvarying anxiety over money and the ever present juggling is a constant drain on my personal physical and emotional resources, and this reduces my ability to help Mihdi achieve the level of success he could, especially academically.”

Mr. Brock has learned that Mihdi, at the age of nine, is unable to read or write at his age or grade level.

It has been recommended that he have individual tutoring.

The time and money required for that is non-existent, however.

“The results of recent tests demand that some focus now be placed on his intellect and learning ability,” his father said.

“He has been assessed by the Sylvan Learning Tutoring Organisation and the cost to help him achieve the level he should be at is \$1,500 per month for hour-long, daily sessions.

“It would be a shame to have come this far with him health-wise, only to have him not able to adequately read and write and acquire the appropriate academic standard necessary to ensure that he can make his way independently in this world.”

All these concerns lie behind the tiny family’s most recent appeal for funds.

Mr. Brock is not just begging, however.

He would like to offer up some of the skills he has developed in dealing with Mihdi’s illness to others through a Qi Centre – but this project remains very much stalled at the idea stage.

“It (would be) a vehicle through which I hope to provide assistance to employers and employees, as well as others, from the knowledge I have obtained in this effort to save Mihdi,” he said.

“The time to market the programme is not available at the moment, thus it has not gotten off the ground as yet. I hope that I will be able to bring it to Bermuda so that local businesses can implement it and reduce health care costs.”

How much time is left in the day, however, Mr. Brock must ask himself.

“Some ask, ‘what is the purpose of life’ and others wonder ‘what the future holds after achieving the goals in their lives’,” he said.

“These are not questions that I have. Mihdi will require me to assist him in his struggle for life and mental capacity for at least the next seven years until he effectively stops growing.

“Dr. Wu says it will be for the rest of my life.

“That is what I’ll be going for, and in the meantime, I’ll be looking for ways to support myself and family once Mihdi no longer requires the intense care and treatment that he does now.”

He hoped Bermudians understood how extremely grateful he is for their support of “the mission”.

“I am grateful to Bermudians for the support that they have given and I want them to know that I am not living the life of Riley – we live from hand to mouth, but he has not missed a treatment in the last six months.”