Child of the Month

By Rich Petersen

Daniel Eloy Juárez Gutiérrez

This cherubic face belongs to Daniel Juárez Gutiérrez, known as “Dani” at home. Dani is 10-1/2 years old and lives in Ixtlahuacán with his parents and an older brother. Dad’s name is Omar and is a jewelry designer and also repairs jewelry; Mom, Hilda, is a housewife.

When Dani was just one year old his parents noticed he was having trouble walking and that he fell down a lot, but at that age many children have those problems. However, by age two, Dani was still not walking well, so his parents took him to an IMSS doctor. At that time in her life, Mom was working and had health insurance for the family.

Unfortunately, IMSS at that time (8 years ago) was unable to come up with a diagnosis and said

that Dani would “probably outgrow the problem.” The family continued with appointments every six months, but after another year had gone by and Dani was no better, they went to another hospital where electrical stimulation tests were performed and the diagnosis was immediate—and not good.

Dani was born with a type of muscular dystrophy known as “Duchenne syndrome,” caused by a defective gene for dystrophin, a protein in the muscles. This type of muscular dystrophy is characterized by its rapid progress throughout the body. There is no known cure to date for this; only physical therapy and anti-inflammatory medications are of use in helping the patient continue to have good muscle function. More males than females have this type of M.D., and many times there is no antecedent family history (as in Dani’s case). His parents know of no one in their respective families who has had this type of problem.

With the love and care and help of his family, Dani is doing pretty well at this stage. He is good in school (loves arithmetic, especially division) and loves to draw and color cars and tanks; he even tries to design his own models on paper. He is social and has a sharp mind, and is very nice to be around.

Kudos also to our friends at Shriners International who loan us at Niños Incapacitados wheelchairs for our patients who need them. You might be able to see in the photo that Dani is in a Shriners wheelchair. Up until a few months ago, he was able to walk a bit on his own, but due to the rapid progression of this type of M.D., he is now confined to a wheelchair.

Dani goes to therapy 2-3 times a week at Teletón, a Mexican-run facility in most large cities for physical and other types of rehab. The doctors at Teletón have strongly recommended that Dani have a motorized wheelchair so he can be more independent and get around on his own. At the moment he can manage his regular chair, but, again, this disease will quickly take away the strength he now has in his arms.

We at Niños Incapacitados are wondering if anyone here at Lakeside knows of a motorized chair that is no longer in use and could be donated to Dani. The cost of a new chair of this type is around $2,700 U.S. The folks at Teletón have committed to paying one-half of the cost and we at Niños Incapacitados can help with *some* of the remainder, but not all. Should you or someone you know be of help to this great little boy, please contact me at ric hpete@laguna.com.mx

If you would like to meet other children being helped by Niños Incapacitados, please attend our regular monthly meetings on the second Thursday of each month in one of the meeting rooms at the Hotel Real de Chapala in La Floresta. Coffee and cookies at 10:00, meeting at 10:30. Bring a friend. You will learn how you can volunteer in many different ways and how your monetary support helps so much to assist needy families whose children suffer from a chronic and/or debilitating illness or condition.