

# MATTHEW CULBERT

## COMFORTABLE IN HIS OWN SKIN



Matthew received two rare and very high judo honours this year – a steward tie and a brown belt.



BY LAUREN MANDARINO

Matthew Culbert, Class of 2018, received a brown belt and a steward tie in judo this year – two rare and very high honours. In the 19 years that Sensei David Miller has been teaching at Royal St. George's College, he has awarded approximately 15 brown belts (the highest level awarded at the College) and three ties.

The achievements are well deserved. Matthew, who was introduced to judo when he started at RSGC in Grade 7, does not compete in the martial art, but he is extremely dedicated and works closely with Sensei to run and deliver the after-school judo program. He also spends a lot of time teaching and training.

What is unique about Matthew is that underneath his judo gi, he has a rare skin condition called epidermolytic hyperkeratosis that makes it a challenge every time he steps on the mat.

"Sometimes I come home looking like I've been in a fight," said Matthew, who was born with the genetic condition. "My skin cuts really easily, so I pay a little bit of a price sometimes. Of course, sometimes I don't cut myself at all. Whatever the case, it's worth it."

Matthew explains that his skin is missing the under layers, which makes his body constantly think it is injured. His body, therefore, heals extremely quickly, but also takes on a very rough, scaly appearance.

His mother, Denise Loft, explains that Matthew's skin is incredibly fragile.



Matthew, his sister Emily, mother Denise and father Brian enjoy spending time together whenever they can.

"A little bump to most people will break his skin," she said. "After a judo session, Matthew will have cuts on his nose, knuckles, eyebrows and feet. Sensei Miller bought this special tape, so he can bandage him up when need be."

What Matthew doesn't know is that before he started judo in Grade 7, Denise almost emailed Sensei to tell him about her son's skin condition and that she didn't think it would be a good idea for him to get involved.

"In the end, I decided not to send the email and figured I'd just let it unfold. And look what happened," said Denise. "I think sometimes as parents, we protect our children too much and we should let them blossom. We have our own preconceived notions about what's going to be bad for them. Can you imagine if I had actually sent that email?"

Certainly life at the College would have been very different for Matthew, who spends so much time in the dojo. Not only has judo been extremely good for his self-confidence and helped Matthew overcome challenges, but it has also helped him build a strong relationship with his mentor, Sensei Miller.

Sensei is impressed by Matthew's eagerness and leadership skills, his interest in the philosophical aspect of the martial art, his remarkable natural ability and his tremendous instincts. But he knows these haven't come easily.

"His determination and resolve to succeed gave him the tenacity to push through any of the challenges that he was facing," said Sensei, who says that

Matthew is one of the most skilled judo students he has ever had. "But nothing came easily or without a price. Every time he stepped on the mat was a physical challenge for him, yet he did it with a smile and amazing positivity."

Sensei is also proud to say that having Matthew in his life makes his life better.

"There's definitely going to be a void in my heart and in the dojo when Matthew graduates," said Sensei.

"Matthew is really special because he has decided who he wants to be. He is creating Matthew, which has been a big part of his personal evolution. He enriches the lives of people around him and he's also being really true to himself."

Matthew has, in fact, been working really hard to be true to himself. In a world where he was born looking different than everyone else, he admits that some days are harder than others to get through.

"I wish I could say that it's always sunshine and rainbows, but it's not. With stuff like this, you just have to learn how to be yourself and try not to act like you're something you're not. You'd have to keep that act up every day, which is really hard," said Matthew, who often has to deal with spontaneous cracking, bleeding or extreme itchiness in the winter. "The most important thing is to stay close to your family and loved ones because they're always there for you when you need help the most."

Denise and her husband Brian Culbert are certainly there for Matthew and are so happy to see him thriving – especially after his touch-and-go entrance into the

world. Within an hour of Matthew's birth, the family was at SickKids hospital, where they remained for several weeks.

"We had the fear of God put in us when he was born," said Denise. "We were so grateful that we had a baby we could take home."

Epidermolytic hyperkeratosis is an extremely rare condition that affects approximately one in 250,000 people worldwide. Unfortunately, because of its rarity, no research is being done into a cure. Matthew grew up knowing he was unique and he embraced it.

"When he was little, he thought he was special and different – he thought he had superpowers because his skin grows at a very accelerated rate and heals so quickly. Mosquitos also couldn't penetrate his skin, so they wouldn't bite him," said Denise. "He saw it as a benefit."

The fact that he looks different, that people look at him funny or make comments was a challenge he had to learn to deal with. Denise said that she and Brian taught him at a young age that looking different was a good thing.

"We always told him that he was lucky his skin disease was a visible thing, so that when people would meet him, they would know right away that he's different; whereas if someone had something wrong on the inside, like their heart, people wouldn't know," she said. "Because of that, he could make true friends because they would know what he was like on the inside."

And what he is on the inside is pretty special.