Remembering Dr. Miroslav Kovacevic

A personal tribute from the families of Dr. K.

Dr. Miro Kovacevic (aka “Dr.K” to his patients) was a shining star of guidance, support and miracles to so many families who were lost in the wilderness of pain and suffering in the darkest times of their lives. Highly intelligent, creative and socially vibrant children are suddenly launched into an unknown world of agonizing irrational and paralyzing fears, compulsions, and a myriad of debilitating symptoms resulting in a sharp turn inward. No one who hasn’t lived through it can understand it. Doctor after doctor cannot explain why this is happening, if they believe the patient at all, and they can’t or won’t spend the time necessary to help. So the family is isolated, alone and helpless to save their child. These are the patients and families Miro Kovacevic dedicated his life to saving. After Dr. Susan Swedo at NIH and her early colleagues discovered the disorder called PANDAS in 1998, she came under blistering attack by adult and child neurologists who had no experience with such patients. They forced clinicians and researchers wanting to pursue what Dr. Swedo found to abandon these efforts… leaving innocent children, who because of an infection, were suddenly trapped alone in a world of torture with nowhere to turn. Suddenly a son or daughter, brother or sister, was unrecognizable and the family finances were drained and relationships were strained. The despair of not being able to help your child is unfathomable and for 15 years, before PPN or parent groups were established, this was the situation.

Then around 25 years ago, Dr. Kovacevic, who knew nothing about PANDAS, had a friend call him in great distress and ask for help. After a long flight with his family, the friend explained that his young son suddenly became incapacitated by severe OCD, an inability to speak or even to eat. Unsure what to do, Dr. K came upon the Swedo NIH paper. Then he did what most doctors would never risk; he followed the Swedo protocol and gave the young boy IVIG. Within an hour, while Miro was administering the treatment, the young boy suddenly spoke “Dr. K, I’m hungry, can I have a hot dog”. And then the boy ate one. Miro said “I had witnessed a miracle”. That incapacitated boy fully recovered. Over time, other doctors may have directly or indirectly observed the same phenomenon but it was easier to look the other way or chalk it up to coincidence or luck. Not Dr. K. His heart was bigger than his ego and larger than his pride. He genuinely cared about his patients, and started treating more kids and seeing similar results. By the time he passed away last week, he had treated over 6,000 patients and inspired a new IVIG study at NIH which again showed a dramatic decrease in OCD. Yet, when the findings were written off by the same small cohort of neurologists, and he was ridiculed and attacked by those who were threatened by his findings or the idea that “just a suburban pediatrician with an accent” he’d say with a smile, could successfully and significantly reduce or stop tics or OCD in children when those at top medical universities could not, he just kept working and helping patients.

Dr. K was an expert in pediatrics, vaccines and diseases involving the immune system. He was an old school physician with a high, modern intellect. He knew that a PANDAS child, who was in a constant state of fight or flight, distrusted medical professionals and had been subjected to endless blood tests, psychological treatments, failed medications often with serious side effects and false promises of recovery. So when such a child entered his office in Hinsdale, IL, he immediately would disarm them - with his unique wit, charm and humor. And while he was doing so, he was also observing - the unusually dilated eyes of the patient, which parent was falling apart and which was able to cope. He would play to all of their fears and strengths. And within 15 minutes, that PANDAS child trusted him… and only him. They had a new friend. Someone who understood and believed them. And the mom or dad cried in that first visit as they too finally had a doctor who believed them as well. Dr. K would often say of the parents

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“why should I believe a doctor’s report who was with your child for 15 minutes when you have been living with them every minute from the time they wake to the time they go to bed”.

Then these children, riddled with fears so severe they could not leave their home, or room, or bathroom, trusted Dr. K to do what others would not - 2 days of IVIG treatment in a medical facility and then follow his critical protocols post treatment (to prevent relapse and allow healing). PANDAS treatment does not end after treatment - there are endless questions for Dr. K- what if my child relapses?, or gets strep?, a cold? runs a fever? has to see a dentist? He would get up each morning and answer those questions from parents all over the world who had come to see him. He had no junior physician. He just didn’t trust them to handle his patients. And for most, his patients recovered either quickly or over time - either from a single treatment or multiple treatments. And for those whose immunotherapy didn’t work, he would never stop thinking of alternative treatments and try to figure out scientifically why they failed treatment.

Many clinicians and researchers, especially those critical of PANDAS, are focused on peer recognition, grant money, getting published, publicity and feeding a fragile ego. But, while everyone else was focusing on these endeavors, Dr. K was achieving one miraculous recovery after another. He never boasted about it nor told anyone. Not even his own family. He was humble to the core. He focused on the patients and searching for answers as to why they reacted to infection as they did. He was also a meticulous record keeper. He recorded not only the large black pupils, but also unusual severe separation anxiety - ten year olds who suddenly would not leave their mother’s side or had to sleep in their parents beds again. He documented the child or teen’s dysgraphia - inability to draw before treatment, like a house that was completely abstract before treatment and totally defined afterwards. He even restored a young artist’s ability to create and paint again.

His findings reinforced what NIH found in 1998 with some additional observations. For instance, he noticed that it didn’t matter if the patient was 3 years old, 13, 23 or 33 they all could exhibit the PANDAS symptom set. Until Dr. K, a PANDAS diagnosis was limited to pre-pubescent children only. Teens and young adults suddenly struck down by PANDAS were out of luck… with no diagnosis and no one willing to help. Dr. K was one of only a small handful of doctors in the US willing to diagnose and treat teenagers and young adults with PANDAS symptoms. Additionally, before Dr. K, the conventional thought was that if the patient waited too long post the onset of PANDAS, the die was cast and immunotherapy like IVIG would not work. This was a devastating prognosis if your child was diagnosed too late. However, Dr. K proved the thesis wrong and treated many patients successfully 5, 10 and 20 years after their PANDAS onset - some now in their mid 30s. These findings and his statistics on the constellation of PANDAS symptoms his patients were experiencing played a significant role (along with a few other brave physicians) in facilitating the widening of the PANDAS definition by NIH to PANS - Pediatric Acute Onset Neuropsychiatric Syndrome. Though Pediatric is in the title, the diagnostic guidelines now provide that a teenager or adult who experiences the symptoms of PANDAS, or also has anorexia-like restricted eating (not in the original PANDAS definition), could be diagnosed and treated. This was a total paradigm shift in care and treatment. Suddenly approximately 10x the number of afflicted kids could be diagnosed and treated.

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Moreover, many hospitals won't allow severe PANS or PANDAS patients to be treated with immunotherapy in their facilities because they are too difficult. Dr. K did not send these impaired children and their severely damaged families to hospitals or acute care centers for treatment because he knew it would be traumatic for the children and he would lose control. Instead, he insisted that the patient and parent(s) fly to Chicago where they would be treated over 2 days in a third party treatment center near his office. There the nurses knew how to handle these kids and their unique set of symptoms and more importantly and unbelievably…he was always there with them. For two consecutive days, hours at a time, he was there at the infusion center. Upon arrival, when the idea of a PICC line or so many items in a hospital-like treatment center could set off a myriad of OCD fears and compulsions, he immediately disarmed the little boy or teenage girl, as only he could do, so the line could be safely inserted and the patient would stay for two days with limited anxiety and fear. All the while, he was reassuring and kibitzing with the parents and constantly checking, and keeping the patient at ease.

His was a reassuring hand pulling them out of the depths of despair.

For the many families Dr. K helped throughout the years, either through treatment or counsel, the significance of his passing cannot be understated. We lost the reassuring, knowledgeable voice. We lost a friend. And we lost one of only a few left who have 25 years of experience with these patients, especially the severe cases. We will miss his pointing PPN in directions of research to explore stemming from his experience at the bedside. We will miss his detailed and anecdotal accounts that made their way to the PPN website.

Dr. K selflessly spared his family from the daily torture of PANDAS symptoms that he witnessed every day. So, for his family, who perhaps doesn't know the full extent of the impact their father, grandfather and husband has had on so many, please know that he left this world a far better place. He did so with kindness, humor, respect and extraordinary generosity for his patients, their parents and for his colleagues.

Each year, countless individuals and families turn to PPN for information, guidance, and resources, many of whom have benefited, directly or indirectly, from Dr. K's work, which has saved countless lives. Thousands of families are grateful to him and especially his young patients who because of him, can one day have families of their own who may in turn make a difference like he did.

The darkness of PANS and PANDAS is so all encompassing and endless, that it's often hard to describe. We just lost our light leading us out of the darkness.