

If I Were Prime Minister . . .

By

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A Message to a Boy Facing a Serious Illness

(1)

The family of one of my wife's friends, living in Germany, stayed with us again this year. It was an enjoyable summer visit.

My wife's friend is Japanese, and her husband is English. Currently they live in Munich, Germany for work reasons. They are a family of four, with a son in eighth grade and a daughter in high school.

We played bridge together while the children worked up a sweat playing with our family dog, a Westie named Beethoven, and the duck named Chopin who lives in our garden.

The boy, who seemed a little young for his age, had a good time frolicking with the dog and the duck, the three of them looking like three crows. Chopin the duck chased the dog while quacking loudly, and as the dog ran away barking the children screamed, waved their arms, and splashed around, like a scene from a musical. I enjoyed watching the boy in particular. To me he looked like a dancing angel.

In the evening we had a barbecue in the yard. While our meal consisted mainly of meat, since my wife's friend's 193-centimeter-tall husband was a vegetarian he mainly ate seafood and vegetables. We all enjoyed the dinner together, and everybody commented on how delicious the food was.

The women continued talking incessantly, as if they could never run out of topics for conversation.

About one week after this family went back to Germany, the mother hesitatingly told us that the eighth-grade boy had Crohn's disease.

Judging from the name alone it sounded like a serious disease, and I was saddened to hear from my wife the details of the affliction. I immediately asked my doctor about Crohn's disease, and he found for me some information about it from the Internet.

After thinking about various aspects of the situation, I asked my wife to send a sensitive email to her friend.

(2)

•**Email to Germany (August 2012)**

My husband says he was quite shocked to learn about your son's Crohn's disease.

He says that while striving to think of something he could do or some way he could help, as he tried to keep his presence of mind he remembered something from long ago.

While the shadows of this episode in his life still linger today, about 40 years ago my husband was diagnosed with tuberculosis of the lungs and told by his doctor that he might need to be hospitalized in the coastal city of Atami. At that time, tuberculosis was an untreatable disease whose victims ultimately ended up dying as they coughing up blood, and the term "hospitalized in Atami" carried with it the implied nuance of being kept in isolation.

My husband says that he decided that if he were going to die anyway he would go to the hospital neither as an outpatient or an inpatient but instead would just let time take its course.

Then one day the hospital contacted him unexpectedly, asking him to come in to be administered a new drug. He says that the people in the hospital told him the drug had come along just in time.

After about one year of medication, the tuberculosis was healed, but then he developed rectal cancer. This was followed by other complications including a lymphoma that was described as untreatable, laryngeal cancer, and the need for surgery for a related aortic aneurysm. He underwent a very tough period of hospitalization. Still, his doctor kept telling him that he would heal, and inspired by these encouraging words he tried to recover. Today he is in good health.

As it has been more than 10 days since your family returned home, I think

that, in many senses, we now are able to make a calmer judgment on the situation. Of course we hope that your son will get better, but we understand that there is nothing we can do for him or for your family. We cannot even provide moral support. We understand that even though we want to lessen the burden on your son and your family, our efforts to do so might seem to you to be more of an annoyance than a help.

Still, my husband and I have decided that if we were to remain silent out of fear of offending you, then there definitely would be no way we could help at all.

While simply repeating the same thing over and over again will never lead to progress, one still can expect some positive changes to take place. The future often brings changes. One never knows when a complete cure might appear.

It appears that right now Humira (formally approved for use in Japan in October 2010) is the best medicine for Crohn's disease, but because it is so expensive many doctors choose Cimzia (not yet approved for use in Japan as of 2013).

We would be truly happy if we could help in any way to reduce the burden on your son and your family.

While we understand that this offer may offend you, we have concluded that we would like to help support you by reducing the burden of your son's high medicine costs until he is completely cured.

We hope that after his illness has healed he will extend a hand to the numerous people around the world who struggle with serious illness, and that when he grows up he will become Prime Minister of Japan, further improving Japan's health insurance system, which already can be described as the best in the world, draft a law to protect patients who have serious illnesses, and make medical care free of charge for all, to build a world in which people with serious illnesses, whether children or adults, can live with peace of mind.

A politician named Shinzo Abe suddenly resigned from the position of Prime Minister of Japan on September 12, 2007. It is said that the reason he stepped down was to devote himself to his treatment for the serious illness of ulcerative colitis.

After repeated treatment, today he is in good health and actively working to

become Prime Minister again.

We will be on Megijima Island from the 12th to the 19th. I hope we can meet on Megijima next year.

(3)

• **Reply to the above email (August 11, 2012)**

It's nice to hear from you again.

Thank you for your wonderful hospitality during our visit.

I am sorry that we were unable to say our goodbyes properly when we left.

I cannot find words to express my gratitude for your warm, heartfelt email of the other day. All I can say is that I am grateful to have such a good friend.

Unfortunately, the text of your email was cut off partway through. If you could, would you please resend the part after "The future often brings changes. One never knows when a complete cure might appear"?

Thank you so much for your concern about our son. To make sure that he will have no regrets about our visit to Japan, he is very busy right now, after being resigned to inoculations at the hospital. He is fully enjoying movies, videogame arcades, and things that he can only do in Japan. While Japanese children are busy with preparatory school and other activities, he is enjoying himself completely! It is like heaven for him as he lives by his motto of doing everything the best he can so that he will be sure to have no regrets. He appears to have decided to live a positive, enjoyable life for as long as he can.

Two years ago, he lost his 10-year-old girlfriend, with whom he had played often. They came to know each other in the hospital as two patients with serious illnesses, and they played together frequently, even visiting each other's homes.

This year, as he looked at her portrait before leaving for Tokyo, he resolved anew to fight his disease.

My son is living a happy life. Fortunately he has made many wonderful acquaintances and he is grateful for that alone. I too would like to provide the moral

support to help him live a normal life for as long as possible.

It is my heartfelt wish that his life will be healthy and happy from now on.

I look forward to meeting with you again in the future. We intend to continue living a happy life just as we have until now here in Munich, Germany, and we hope that you are happy as well.

Thank you again for your heartfelt message.

• **Second reply (August 11, 2012)**

Thank you for sending the remainder of your previous email.

I have refrained from telephoning you because I understand that you are seeing a dermatologist and we too have been somewhat busy.

Thank you for thinking of what you could do for our son and for asking a specialist you know about his case.

He became ill at age seven, and at first he was hospitalized for a year in the pediatrics department of the Medical Center of the University of Munich. After that, in the third year of treatment he was fitted with an artificial anus and other medical implements, and the doctors kept his abdomen open until February of last year. I've lost count of how many times he underwent surgery over that period. He has lost at least one-third of his large intestine.

Now he is under pediatric internal medicine care, taking various medicines, but last year we learned that he had suffered a relapse. Although we thought of going back for surgery, he did not want to do that. Instead, we are continuing the internal medicine treatment. Opening his abdomen again could be a major burden not just physically but emotionally as well. He wants most of all to play with other children at school. My husband and I both decided to respect his wishes.

Actually, he has been taking Humira since May. The level of medical care in Germany is the second highest in the world after the United States. Before he began taking the medicine, he spoke one-on-one with the doctor. The doctor told him that Humira is not yet approved for children in Germany, that the effects of treatment still are unclear, that there is a possibility of cancer arising as a side effect from continued