A Hidden Health Threat

EXPERT RECOMMENDATIONS FOR BETTER MANAGEMENT OF PRIMARY IMMUNODEFICIENCY (PID) IN MALAYSIA

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MyPOPI

2017

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Appendices

-Living with PI/Patient Stories-

Name of patient: ADAM ZAQUAN MOHD RAFIZI BIN ABDUL HAQQ
Age: 7

Name of parent: NINA ZARINA BINTI ROSLAN
Age: 26

Diagnosis

Adam Zaquan, anak sulung saya dilahirkan normal seperti kanak- kanak yang lain pada 21 July, 2010. Pada usia lapan bulan dia kerap mengalami demam panas suhu tinggi hingga mencecah 40° serta di jangkiti bronchiolitis dan mengambil nebuliser di hospital. Selepas beberapa bulan kemudian genap usia Adam Zaquan 1 tahun 6 bulan dia telah dimasukkan ke PICU HKL kerana dia diserang penyakit staphyylococcus toxic shock syndrome with varicella zoster infection. Keadaan dia tenat dan dia terpaksa dibantu dengan menggunakan mesin oksigen di PICU HKL.

Apabila Adam Zaquan dimasuk ke ICU dan demam tinggi di Hospital Kuala Lumpur, anak saya dirujuk kepada pakar imunologi iaitu Prof Intan Hakimah dari Hospital Serdang. Adam Zaquan mendapat diagnosis penyakit lebih kurang Disember 2015. Pada ketika itu Adam berusia 5 tahun dan dia jatuh sakit lagi kali kedua. Saya dikejutkan apabila Adam Zaquan demam tinggi tanpa surut, demam serta bintik-bintik merah kecil timbul di kaki dan ibu jari dia kemudian bertukar keungguan dan kehitaman.

Saya terus bawa dia ke HKL untuk menerima rawatan, sampel darah diambil, dan keputusan menunjukkan kiraan darah putih terlalu rendah. Kemudian doktor menyaran untuk masuk wad. Apabila masuk ke wad keadaan dia tak tentu arah seperti mengalami sakit yang teruk sehingga tingkah lakunya menjadi agresif. Apabila doktor pakar melawat kami, dia mengarahkan Adam Zaquan dimasukkan ke PICU untuk kali kedua. Kali kedua berada di PICU keadan dia makin teruk dari kali pertama di PICU.

Rawatan

Anak saya menjalani rawatan IGIV (3 kali seminggu) 12g=4 botol (3g per botol) mengunakan tubing dan jarum ke dalam salur urat. Tidak mudah untuk mendapatkan bekalan ubat yang secukupnya

bagi setiap pesakit PID kerana bekalan terhad. Dos yang anak saya terima kurang dari dos sepatutnya. Kesan sampingan pada anak saya adalah kuku kaki akan merekah dan mengelupas.

Penjagaan

> …saya mohon untuk menubuhkan satu wad khas untuk semua pesakit PID sahaja yang mempunyai doctor pakar bidang imunologi serta jururawat khas untuk mengendalikan pesakit PID sahaja

Rawatan dari kanak-kanak ke dewasa akan menjadi sukar apabila anak saya meningkat usia 18 tahun kerana rawatan IGIV kini anak saya lakukan di daycare pediatrik hospital Kuala Lumpur. Tambahan lagi daycare yang anak saya lakukan rawatan IGIV itu adalah di utamakan untuk pesakit onkologi kanak-kanak. Pesakit PID seperti anak saya tiada jururawat khas untuk mengendalikan tranfusion IGIV kerana semua jururawat boleh uruskan mana-mana pesakit, bukan hanya fokus pada satu-dua pesakit dalam satu masa. Oleh yang demikian, anak saya kerap mempunyai masalah dos ubat tidak mencukupi, sampel darah yang perlu diambil tidak diambil tepat pada masanya.

Saya berharap agar ada pihak yang berwajib ambil tindakan sewajarnya untuk mengubah cara penjagaan pihak hospital kepada kanak-kanak PID pada masa kini. Dan saya mohon untuk menubuhkan satu wad khas untuk semua pesakit PID sahaja yang mempunyai doktor pakar bidang imunologi serta jururawat khas untuk mengendalikan pesakit PID sahaja.

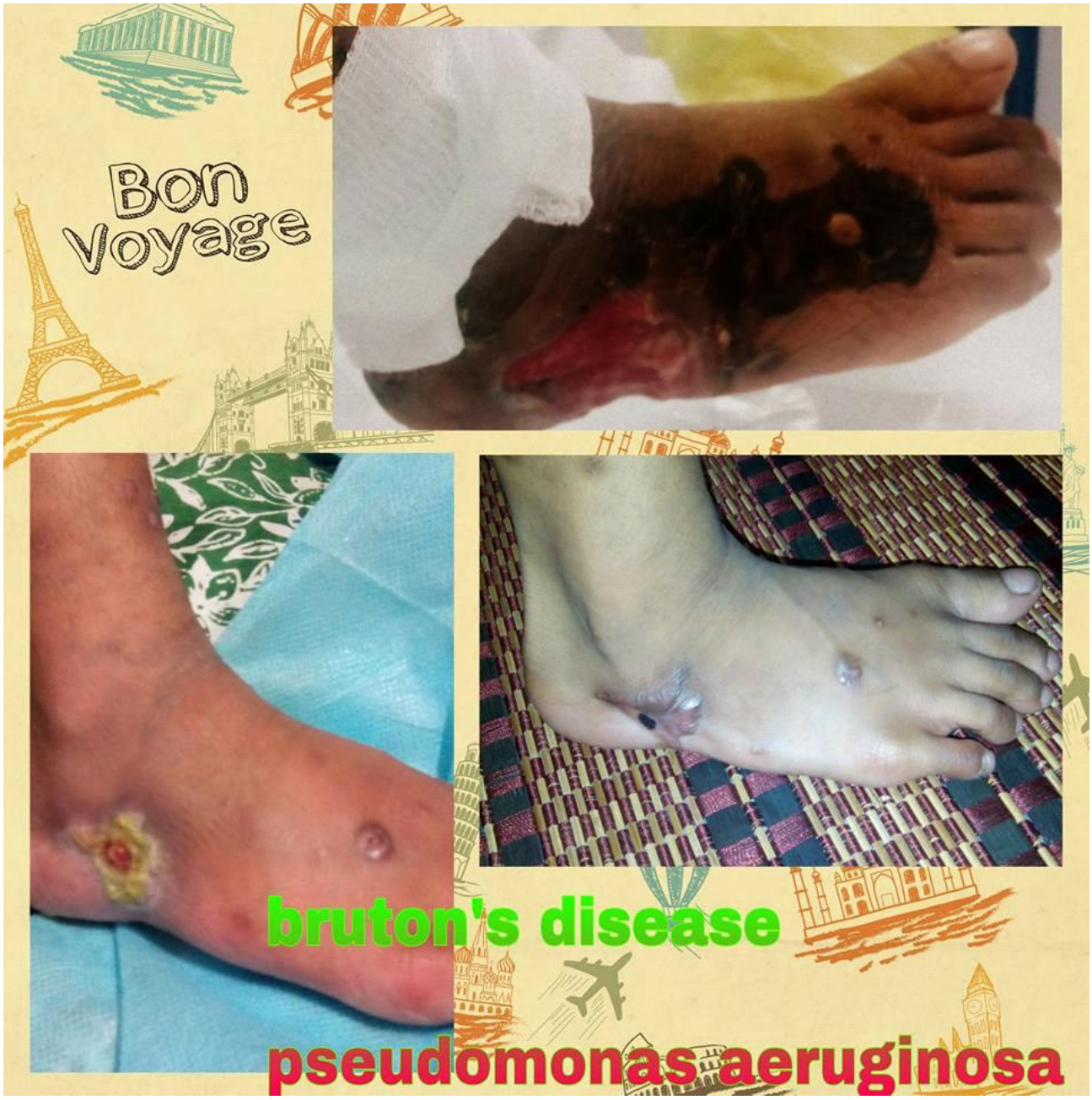
Kesedaran

Saya juga mencari maklumat di Internet untuk penyakit PID ini sekadar untuk menambah pengetahuan tentang penyakit ini.

Matlumat tambahan

Adam Zaquan menerima diagnosis penyakit PID ketika berusia 5 tahun

Kali pertama dimasukkan ke ICU ketika berumur 1 tahun 6 bulan



Adam Zaquan diserang kuman pseudomonas aeruginosa (November 2015)

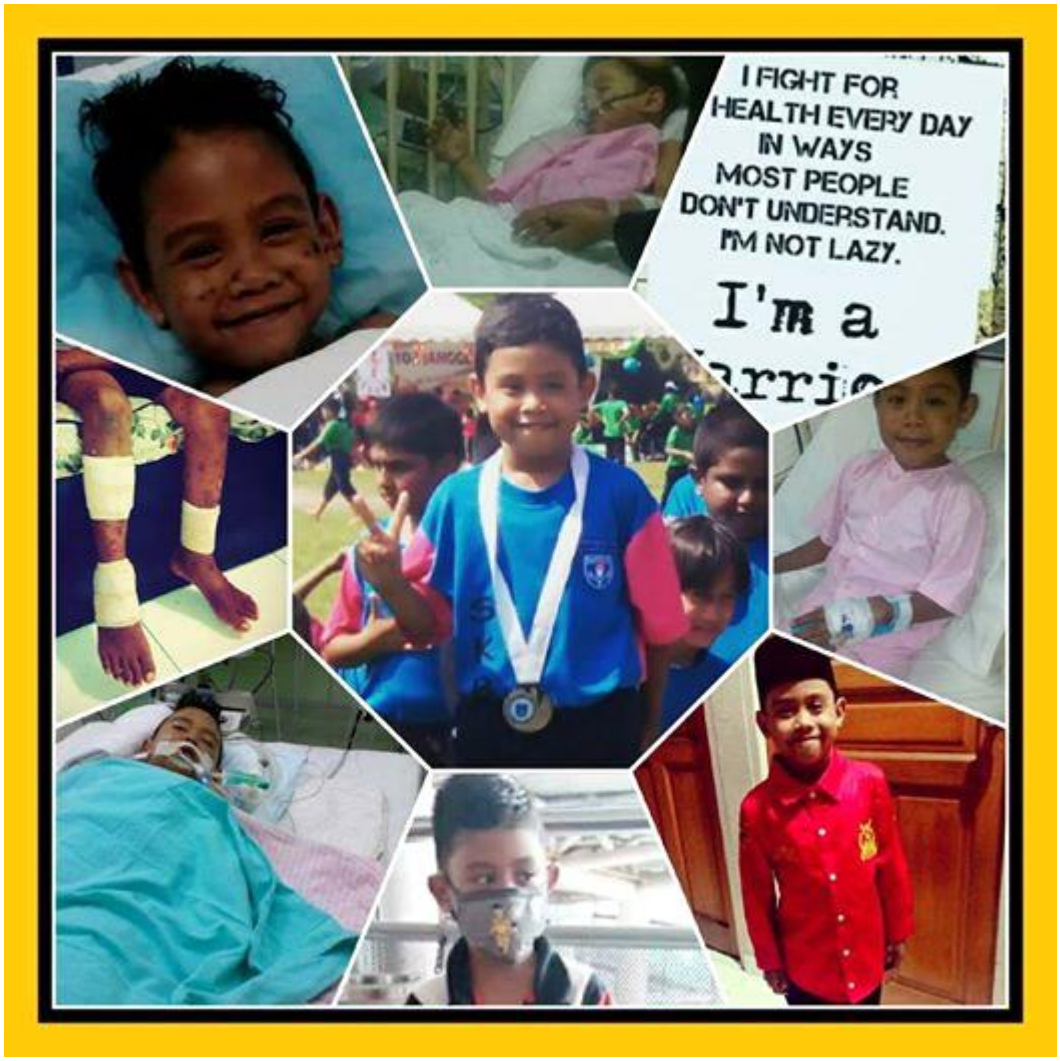
Kali kedua dimasukkan ke ICU (November 2015)

Dua minggu selepas Adam Zaquan sedar (November 2015)

Masih mampu senyum walaupun dalam kesakitan

Dibenarkan discharge dari Institut Pediatrik HKL (December 2015)

Tiga minggu sekali menerima rawatan IGIV di day care Institut Pediatrik HKL



Adam Zaquan dalam proses pemulihan

Name of patient: ANIS ZULAIKHA BINTI ZULKEFLI
Age: 20

Name of parents: NORHASIMAH OTHMAN and ZULKEFLI MOHD GHAZALI

Diagnosis

We realised something was wrong with our daughter when she was 1 month old. She had been repeatedly admitted to various hospitals including the Paediatric Institute at HKL, Ipoh Hospital, Seri Manjung Hospital, and University Malaya Medical Centre because of lung infections. At 3 months old, it got worse and at one point the doctor had to ventilate her lungs for a week. At 2 years old, she was diagnosed with Myelodysplastic Syndrome (MDS). Autoimmune screening was only carried out on 4 November, 2009 after a few episodes of infection requiring antibiotics administered intravenously at the Paediatric Institute, HKL.

It took 12 years for my daughter to receive the correct diagnosis, which is Common Variable Immune Deficiency (CVID). When we were in Hamburg, Germany from 1999 to 2003, she was admitted to hospital once because of a lung infection. Anis was given a blood test and the paediatrician later informed us that MDS had been ruled out.

Treatment

She has to undergo IGIV every month and use an inhaler (Flixotide). Treatment is not available at Seri Manjung Hospital. She has to travel from Lumut to the Institut Perubatan Respiratori (IPR) at HKL every month accompanied by her mother. There have been no adverse reaction or side effects. In fact since her first IGIV, she has not had any lung infection that requires her to be warded.

Care

The problem is that there is no immunologist at HKL-IPR. Very few nurses are trained to

administer IGIV. This causes delays during treatment, hence prolonging Anis's stay at day care. When she was a child, she only got to see the paediatric immunologist from HUKM every three months and later every six months. She has been given immunoglobulin replacement therapy (IRT) through chemo port because it is just difficult to find a good vein. On many occasions when she was at the Paediatric Institute HKL, treatment had to be delayed for a few hours because of the difficulty in finding a good vein.

Awareness

The doctors had explained about the disease. We complement the knowledge provided by searching the web. Since there is no immunologist in HKL, we have to be satisfied with the three monthly check-ups with paediatric immunologists from HUKM and UPM. Whenever Anis is down with a fever, she has to get treatment at nearby hospitals or clinics. Medical officers know very little about both MDS and CVID.

Name of patient: CALEB LIM
Age: 13

Name of parents: BRUCE LIM WEE DIONG & KAREN KOH YAH HUI
Age: 41 (Karen)

Diagnosis

Caleb was born on 22 February 2004 a perfectly healthy baby at full term and at a healthy weight of 3.8kg. He developed jaundice a few days after his birth and was treated with phototherapy. The jaundice went away after the phototherapy treatment.

After Caleb turned 1, he was always sick and had a history of recurrent pneumonia and bronchitis. Yet the paediatricians, and ear and lung specialists who treated him didn't suspect that something was amiss. He was always given either oral or intravenous antibiotics to treat the infections but they kept recurring afterwards. Even the treating paediatrician couldn't figure out what was wrong with my son, why he was always sick and prone to infections compared with other children of the same age.

In August 2008 (when Caleb was 5 years old), he developed a right lower lobe pneumonia complicated by empyema requiring right thoracotomy (lung surgery) after antibiotic therapy and drainage failed. He was admitted and treated in the hospital from 29 August 2008 to 20 September 2008. In addition, Caleb had a few episodes of otitis media, the latest in June 2008, requiring drainage and insertion of bilateral grommet tubes.

On 30 September 2008, Caleb developed high fever and had recurrent pneumonia whilst on holiday in Melbourne. He was sent to Bulleen Plaza Medical Centre for consultation and was immediately referred to the Emergency Department of Royal Children's Hospital Melbourne (RCHM). At RCHM, he was first attended to by Dr Danielle Wurzel, respiratory fellow at RCHM. The first thing Dr Wurzel asked us was a chronology of Caleb's medical history. After giving her a chronology of Caleb's history of recurrent infections and hospital admissions, Dr Wurzel immediately suspected abnormalities of the immune system and did some blood tests under the care of Dr Sharon Choo, consultant immunologist and immunopathologist at RCHM. The results of the blood tests showed extremely

low level of serum immunoglobulins including IgG (0.42), IgA (<0.06) and IgM (0.12), panhypogammaglobulinemia with undetectable Hib and tetanus antibodies, suggesting a primary antibody deficiency.

Due to Caleb's acute illness (and its possible interference with the accuracy of results), a full immunodeficiency screening was not performed during admission at RCHM. RCHM recommended that blood tests and immunology review be conducted upon return to Malaysia. Caleb completed five days in total of IV antibiotics in RCHM and then completed four weeks of oral antibiotics when he was back in Malaysia.

Caleb came back to Malaysia on 5 October 2008. Copies of his blood results taken at RCHM were emailed to Caleb's local paediatrician and it was recommended that Caleb be reviewed urgently by a specialist immunologist or haematologist. Caleb's paediatrician referred him to a haematologist at Universiti Malaya Medical Centre (UMMC). On 20 October 2008, Caleb went to UMMC for his first consultation. UMMC repeated the blood tests and the results were the same as RCMH's. On 17 November 2008, the diagnosis was finally established after further blood tests were carried out. Caleb was diagnosed with X-Linked agammaglobulinaemia (XLA). However, we were not referred to an immunologist.

After Caleb's diagnosis was established, the only treatment that was recommended to us by the haematologist at UMMC was a bone marrow transplant. The consultant haematologist explained the procedure and its associated risks. The haematologist recommended that Caleb undergo the transplant as soon as possible. We were not comfortable and decided to seek a second opinion so we contacted RCHM. We were immediately informed that the bone marrow transplant is not the appropriate treatment to manage Caleb's condition because of its high risks. RCHM urgently recommended that Dr Liew Woei Kang, an immunologist at KK Women's and Children's Hospital (KKH) in Singapore who trained at RCHM, review Caleb.

Treatment

We met Dr Liew Woei Kang at KKH in Singapore and Caleb received his first intravenous immunoglobulin infusion in KKH Hospital, Singapore on 24 November 2008 with no adverse

reactions. We were given a very thorough explanation on XLA and counselling on the management of the disease. The recommended management plan for Caleb included:

- Lifelong intravenous immunoglobulin (IGIV) replacement therapy (3-4 weekly infusions of IGIV)
- Perform a trough level of IgG prior to each IGIV infusion
- Aggressive treatment of chest/moist coughs with antibiotics

With our consent, KKH extracted some DNA from Caleb for genetic testing of Bruton's Agammaglobulinaemia and liaised with a laboratory in Hong Kong performing BTK gene mutation. This was to assist my family with regards to genetic counselling should there be plans for more children.

Upon his return to Malaysia, Caleb received his second IGIV infusion at Subang Jaya Medical Centre and was later referred to Institut Pediatrik, Hospital Kuala Lumpur, under the care of Dr Amir Hamzah bin Dato' Abdul Latiff, consultant paediatrician and clinical immunologist/allergist. Caleb continued his IGIV infusion at Hospital Kuala Lumpur.

Caleb returned to KKH for an immunology review on 2 March 2009. The genetic test sent to Hong Kong revealed that he has a mutation in the Bruton tyrosine kinase gene in the X-chromosome, confirming the diagnosis of Bruton's agammaglobulinaemia. At this time, Caleb had remained healthy for 3 months whilst on IGIV replacement since his first visit and IGIV infusion in KKH on 24 November 2008.

Since August 2015, Caleb has been going undergoing subcutaneous IG (IGSC) therapy at HUKM under the supervision of Prof Dr Lokman M. Noh (paediatric immunologist). He is being administered 9 vials (90mg) of Hizentra bi-weekly.

When we were introduced to IGSC treatment, we received a thorough explanation about the treatment, the procedure, and its advantages compared to IGIV. Our hope is that in the future, we (rather Caleb) can perform his treatment at home and will not need to skip school every two weeks and we will not need to take leave from work to accompany Caleb to receive the treatment in the hospital.

Caleb prefers the IGSC treatment over IGIV because most of the time, it is difficult to find the vein in his hands, hence it takes up to five to eight attempts to get the needle in place for the IGIV therapy. Even with three weekly treatments of IGIV, Caleb is still prone to infection, especially during the last week prior to his treatment.

Care

Caleb undergoes his treatment at Wad 4B, HUKM under the care of Prof Dr Lokman M Noh as well as the medical officers and nurses on duty. We are glad that the MOs and nurses in the ward are trained by Prof Dr Lokman's team to be able to administer the IGSC treatment for Caleb.

I am proud to mention that as his father I'm able to perform the IGSC treatment for my son from start to end of the procedure. In fact, I will normally train new MOs on the procedure when there is a change in MOs every 3 months. We are looking forward to advancing to home therapy soonest possible so that our son will have a better quality of life with a reduced burden of care, and be able to free up hospital beds for other patients who are more in need.

Awareness

We were not given adequate information about the disease when we were informed about Caleb's diagnosis at UMMC. To make matters worse, we were recommended the wrong treatment. We were really lost and didn't know who to turn to (UMMC did not refer us to any immunologist) or where we could get more information about XLA. Before meeting Dr Liew Woei Kang in Singapore, we had to do our own study about XLA on the web. We also tried looking for a local patient support group or society for XLA or primary immunodeficiency diseases but found nothing.

Name of patient: ELSON WONG
Age: 24

Diagnosis

When I was a child I always suffered from lung infections and always had to stay in hospital. Also, I was always coughing. I was diagnosed with PID in 2002 at the age of 9 following an immunodeficiency screening at Mount Elizabeth Hospital.

Treatment

Previously I was taking 20g of immunoglobulin every six weeks and only recently was my prescription changed to 27g of IG every four weeks by the doctor at Mount Elizabeth Hospital is Singapore. She did not recommend taking it every six weeks and said the amount of immunoglobulin taken should be based on my weight.

Now everything is ok but just after the treatments my body will get itchy. Some doctors say this is normal, while other doctors will give me medicine to apply on the skin but it will still itch.

Care

After I transitioned from the paediatric to the adult ward the doctors seemed clueless about my case as if they've never heard about it before. From childhood until today, all doctors that have consulted on me have been non-immunology specialists.

After I transitioned from the paediatric to the adult ward the doctors seemed clueless about my case as if they've never heard about it before. From childhood until today, all doctors that have consulted on me have been non-immunology specialists.

Now I go to the hospital every four weeks to take the immunoglobulin. Prior to this, before and after the treatment, my blood would be taken to see whether the level is enough or not. Every time I ask the doctor about the results, the doctor would look it up in the computer. In recent months though, the report with the results have not come out and a doctor told me there was no need to do the blood tests anymore because the level is always the same. I was very disappointed to hear this because the doctor didn't offer further explanation beyond the reply he gave.

Awareness

In Singapore they explained in detail so that I understood the diagnosis. It's a genetic condition that I inherited from my mother who is a carrier of the mutated gene. But I soon realised that many doctors don't know about this condition and I had to explain and tell them what it is. Only then, do they understand and most of the doctors, if I ask a question, will reply that they don't know or will ask a specialist who also don't seem to have answers for me.

Name of patient: KHANTAN A/L RAJAGOPAL
Age: 37

Diagnosis

My condition was diagnosed when I was 4 years old. I was prone to recurring fever, cough, and flu, and it wasn't easily treatable. So that's when my mom took me to consult a doctor. Only after that was I diagnosed with Primary Immunodeficiency (PID).

The first time I went to see the doctor, he already suspected I might be having PID. It was first diagnosed by Prof Dr Lokman during my first visit with him back in 1985. I was 4 years old then and he did the necessary check-ups.

After a few tests, they tested my whole family. Before I was diagnosed, my eldest sister passed away when she was five years old. After she passed away, they tested my whole family. Once they tested the whole family, they got to know that my sister also suffered from the condition but they could not find out at the time. After that, they determined that I also have PID. It took some months, I can't remember as I was too young. They did a DNA test on my mum, father, basically the whole family. I am lucky because I met Prof. Dr Lokman and I got my PID diagnosis right away even though it took some time because of all the tests. At least they got the diagnosis right.

Treatment

My PID type is congenital. Actually the first treatment I received was immunoglobulin through the intramuscular route (IGIM). A jab was given on my backside muscle, not through my veins. So I get it to my buttocks. It was very painful. Sometimes I couldn't even walk because I was still a child back then. When I was initially on IGIM, IGIV was not available in Malaysia yet. I received IGIM for few a years while Prof Lokman tried to get IGIV treatment. It took him five to six years to get IGIV into Malaysia. It is more effective, I see the difference between the IM and IV. Since I started on IGIV, I have remained with this treatment. At the moment, I am taking it every two weeks in HKL. The

problem is the pharmacists, who will frequently question the nurses who collect the medicine, asking why it has to be every two weeks. This is because the medicine is expensive. So the nurses will then come and complain to us. But I need the medicine, I think it is my right to get it. No doubt it is costly but I have no problem getting it and so far I get it constantly.

Care

It was very difficult to go from being a paediatric patient to becoming an adult patient. I had no doctor to consult and wasn't sure where to go.

The only challenge is that we don't have immunologists for adults so I have been referred to a haematologist. Dr Jameela is from Ampang Hospital and comes to HKL once a month to see me. She also does all the frequent serum Ig tests and everything. So that has increased, previously I was only getting six vials, now it has gone up to seven vials. I am satisfied with what I am getting now, so it is not something difficult.

It was very difficult to go from being a paediatric patient to becoming an adult patient. I had no doctor to consult and wasn't sure where to go. There also wasn't any doctors specialising in immunology. The closest are haematologists and they don't know much. Sometimes, they don't really seem to take any interest or initiative because it is not their area of specialty. They have basic knowledge and I have to try and explain whatever I know to them. Since I've become an adult, that's the way I've been carrying on. Aside from Prof Lokman, a paediatric immunologist who was my doctor when I was a child, I haven't met any other immunologists.

Awareness

I am the one to provide my doctors with information. Even my haematologist says you are your own doctor, but she is very understanding and knows a lot of things about haematology. I have informed

her that I am under Prof Lokman.

My leg was amputated due to an accident and partly because of my condition too; the doctors did not treat me correctly. My leg was put in plaster and then I was sent back home. Six months later, the leg was very badly blistered. When they cut of the POP, there was no skin, they saw only the wound inside, and it wasn't treated with antibiotics. They didn't know how to treat it. So after that I lost all muscle and I can't use the leg. That's the reason my leg was amputated. They know I have PID but they didn't know how to take that into consideration in my treatment. I believe the deficiency in my immune system actually caused that. If they had known, they would have given me a higher dose of IGIV to prepare the body's immune system before they do any surgery or other treatment.

As a PID patient, we need proper treatment. As of now we are not given proper treatment because we don't have proper doctors. This is particularly true for adult patients. So we should have something like a centre or doctors specialising in this to treat people like us. For example, if we fall sick we do not know which doctor to go to. A haematologist's knowledge might not be adequate. But an immunologist will know how to treat us.

Appendix 6

Name of patient: MOHAMMAD HABIB BIN MOHAMMAD BIHIR
Age: 46

Diagnosis

It took 22 years before the diagnosis was made.

My disease manifested through the following symptoms:

- Coughing: Within a few weeks after I was born, I suffered from chronic coughing. At times, there was an increase in phlegm so I had to consume antibiotics. I was hospitalised a few times due to lung infections.

- Skin disorders (5-19 years old): Chronic skin infection resembling impetigo mainly on the elbow, mouth, nose, armpit area, and knees.

- Skin disorders (5-19 years old): Recurrent skin infection resembling erythematous mainly on my hands, thighs, stomach area, and back. Each episode would last around a month.

- Recurrent ear infections (4-26 years old)

- Chronic sinusitis (20-21 years old)

I was diagnosed with PID in 1992 when I was admitted to hospital due to lung infection and was scheduled for an empyema surgery at the Sir Charles Gairdner Hospital in Perth, Western Australia. I was told that I had PID and was started on 27 grams of thrice weekly IGIV infusion. It took 22 years before the diagnosis was made. Initially, I was told I had hypogammaglobulinaemia. However, later

it was confirmed that I had agammaglobulinaemia instead.

Treatment

After the diagnosis was made, I was given IGIV infusion as follows:

- Three weekly IGIV infusion (27 grams) at Sir Charles Gairdner Hospital, Perth, Western Australia from 1992 to 1995
- Once monthly IGIV infusion (27 grams) at Hospital Besar Kuala Lumpur and UKM Medical Faculty from 1995 to 1997
- Once monthly IGIV infusion (27 grams) at Hospital Universiti Kebangsaan Malaysia (HUKM) from 1997 to 1999
- Once monthly IGIV infusion (30 grams) at HUKM from 2000 to 2016
- Three weekly IGIV infusion (40 grams) at HUKM from 2016 to present.

In my case, there are no known complications, adverse reactions, or side effects from the ongoing treatment.

Care

I was under the care of an adult immunologist when I was in Australia between 1992 and 1995. From 1995 to 2016, I wasn't seen by any immunologists. My treatment was monitored by the HUKM Respiratory Clinic. Since 2016, a child immunologist at HUKM Paediatric Clinic is treating me.

I'm currently suffering from bronchiectasis that has developed due to multiple lung infections throughout my life. The most recent result for my lungs is as follows:

- FEV1 : 0.93L (27% of predicted 3.48L)
- FVC: 2.07L (49% of predicted 4.23L)
- FEV1 / FVC (%): 44.5% of predicted 82%
- PEF (L/min): 190L/Min (Predicted 505L/Min)

Apart from IGIV, I am on various other medications and inhalers (Seretide and Berodual). Since June

2015, I’ve been on supplemental oxygen therapy for 12 to 14 hours per day. My current SpO2 (blood oxygen saturation levels) during rest is around 85% to 92%. Keeping my lungs clear of infections is my primary objective to prevent any further degradation to them.

Awareness

There was no adequate information given to me about the disease. I was only given a list of basic dos and don'ts as a guide. No information about vaccination either. Liaising with doctors from other medical specialties was a problem as most of them are not aware of PID. I’ve met skin specialists, ENT specialists and respiratory specialists who had limited knowledge of my condition.

Appendix 7

Nama pesakit: MUHAMMAD FATEH FIRAS BIN MOHD FAIZUL (passed away)

Nama pesakit: MUAMMAR FALIQ BIN MOHD FAIZUL
Umur: 7 bulan

Nama ibu: NORSA'ADAH BINTI ISHAK
Umur: 35

Diagnosis

Anak yang ketiga Muhammad Fateh Firas dan keempat Muammar Faliq yang menghidap penyakit Severe Combined Inmmunodeficiency (SCID). Seawal usia Fateh 4 bulan setengah telah mengalami demam batuk dan selsema yang kerap dan dirawat sebagai pesakit pneumonia. Setiap bulan akan mendapat sakit yang sama dan dimasukkan ke Hospital Seri Manjung untuk rawatan. Pada usia Fateh 6 bulan setengah doctor telah mengesahkan Fateh menghidap penyakit SCID dan dipindahkan ke Hospital Serdang atas nasihat Prof Intan untuk rawatan selanjutnya. Fateh mengalami batuk yang teruk dan disahkan meninggal dunia pada 19 September 2014 semasa berusia 7 bulan 28 hari di Hospital Serdang tanpa sempat membuat pemindahan tulang sumsum.

Pada April 2016 saya telah disahkan mengandung dan telah melaporkan mengenai kehamilan saya kepada Profesor Intan untuk tindakan selepas melahirkan anak kerana bimbang bakal anak menghidap SCID. Sepanjang kehamilan saya mengalami anaemia dan merupakan GBS carrier tetapi telah selesai mengambil antibiotic dan disahkan bebas GBS. Pada 4 Disember 2016 saya selamat melahirkan Muammar secara normal dan cukup bulan (38 minggu) di Hospital Seri Manjung Perak.

Selepas dilahirkan, Muammar telah dimasukkan ke dalam incubator dan dijaga rapi dibawah pemantauan Prof Intan bersama doctor di Hospital Manjung. Pada usia 4 hari Muammar disahkan menghidap SCID, dan HLA Typing di jalankan ke atas anak saya yang sulong dan kedua bagi mengesan sumsum yang sesuai bagi Muammar untuk proses pemindahan tulang sumsum seperti yang disarankan oleh Prof Intan. Selepas empat minggu menunggu, kami mendapat keputusan keserasian sumsum Muammar iaitu dari abang sulong beliau dan Muammar dipindahkan ke Hospital Serdang untuk beberapa ujian.

Rawatan

Sepanjang proses pemindahan dari Hospital Seri Manjung ke Hospital Serdang Muammar ditempatkan di dalam incubator dengan menaiki ambulans sehingga sampai ke bilik isolation di Hospital Serdang. Selepas itu Muammar dipindahkan ke Hospital Kuala Lumpur bagi proses pemindahan tulang sumsum. Pada usia 45 hari (19 January 2017), Muammar telah berjaya menjalani pemindahan tulang sumsum. Selama berada di Hospital Kuala Lumpur iaitu selama 30 hari Muammar tidak mengalami sebarang komplikasi dan keputusan darah sangat baik.

Penjagaan

Muammar dibenarkan pulang ke rumah dengan bekalan ubat-ubatan secara oral dan dijaga rapi oleh kami di dalam bilik khasnya. Perkembangan pertumbuhan Muammar sangat bagus dan selari dengan usianya sekarang tujuh bulan setengah. Kami sangat bersyukur dengan rawatan pemindahan tulang sumsum keatas Muammar dan sangat berterima kasih kepada Prof Intan serta team beliau kerana telah banyak memberi penerangan yang sangat detail bagi penyakit SCID ini. Buat masa ini Muammar diberi ubatan secara oral setiap hari dan masih mengekalkan penggunaan CVL (Central Venous Line) bagi menerima rawatan IGIV setiap empat minggu sekali di HKL.

Kesedaran

Kami mendapat maklumat dari Prof Intan, carian di Google, dan perkongsian cerita bersama Puan Lyn mama Marrisa Hani, dan Puan Latifah mama Azizuddin (rakan-rakan ibu yang mempunyai anak-anak yang juga menderita PID). Tidak ramai orang seperti saya yang megetahui dan memahami mengenai penyakit PID kerana kita mengambil mudah dengan tidak mengambil tahu sehingga ianya berlaku pada diri sendiri. Bagi saya dan keluarga yang tiada sejarah perubatan memang tidak pernah memahami penyakit PID ini wujud. Dimana-mana hospital juga tidak didedahkan dengan maklumat kewujudan penyakit PID untuk pengetahuan umum oleh orang ramai. Disarankan supaya didedahkan lebih terperinci kepada orang ramai di klinik ibu dan anak sebagai permulaan kerana setiap kelahiran mungkin boleh diselamatkan dengan ujian PID yang ringkas seperti soal jawap sejarah kesihatan keturunan.

Name of patient: SARAVANAN A/L VALIATHAM
Age: 36

Diagnosis

Since childhood I've often fallen sick with frequent fever, sinusitis, otitis media, cough, etc. Sinusitis and otitis media were severe and not resolved after repeated visits to the clinic. I was then treated at Dato' Harnam Singh's ENT specialist clinic. Surgical procedures were done twice during childhood due to chronic sinusitis. However the main cause was never discovered until around 1996 or 97.

In 1996 or 1997, I had a severe pneumonia attack which required hospitalisation at GHKL for 20 days. I was treated by Dr Jeffrey Abu Hassan from UKM (UKM shared facilities with GHKL at that time). In trying to figure out what caused my severe pneumonia, only then did they discover that I had congenital hypogammaglobulinemia. If I still remember it right, blood samples were taken and sent to Singapore for serum immunoglobulin tests. The process took a long time and re-tests were done before confirming the diagnosis of hypogammaglobulinemia. From the first episode of pneumonia, it took almost a year before treatment could be started.

Looking back, it took a long 17 years before the correct diagnosis was made. All the while, only the diseases caused by hypogammaglobulinemia were treated.

Treatment

After successful diagnosis, IGIV treatment was recommended and I was treated at GHKL under UKM. I was then transferred to HUKM after the hospital was built in 1997 and continued getting IGIV there. Around 2002, BMT was suggested however I did not get a match from my sibling and IGIV was continued.

I'm still on IGIV. Initially, IGIV was given every four weeks but then it was changed to six weeks due to scarce availability. However, it resulted in recurring infections again and the IGIV frequency was

adjusted to every five weeks. Every time after getting IGIV, I will be ok for two to three weeks and then fall sick again around the fourth week. Frequency is still being maintained at every five weeks with the reason the supply is still scarce and no serious infection to the extent of requiring hospitalisation has occurred.

Many times it takes two to three hours for the nurses to collect the IGIV from the pharmacy and start the procedure (this is often blamed on authorisation issues).

However, treatment is often not done properly at day care where wastage occurs due to spillage as some nurses do not know how to handle IGIV treatment (often poking the needle wrongly on the ampule causing the contents to spill out). Many times it takes two to three hours for the nurses to collect the IGIV from the pharmacy and start the procedure (this is often blamed on authorisation issues). Due to this delay and their need to close day care by 5pm, the treatment is rushed. Nine ampules of 50ml IGIV are given within three to four hours. I often get fever, tiredness, and chest tightness after treatment. It resolves in one or two days.

Care

I was treated as an adult patient since diagnosis. Continuing treatment was a challenge from 1998 after we were hit by the economic crisis. IGIV was no longer given free despite the fact that I was a student at the time. I was required to make full payment for the treatment. Only once, I managed to collect donations and went for one round of treatment. Then, I had to discontinue the treatment as I could no longer afford it and getting donations did not work out as it was a lifelong treatment. Due to discontinued treatment I had multiple episodes of pneumonia requiring hospitalisation which resulted in lung damage. In 2009, I had another severe pneumonia attack which caused my health to deteriorate further. I was categorised under the New York Heart Association (NYHA) class 3 from then on with severe SOB (shortness of breath). I could no longer work and was unemployed for a few years. By the end of 2009, I got myself referred to Ampang Hospital and IGIV was resumed

at 24 grams every two months, which then changed to every three months.

I have never been treated by an immunologist. I was treated by a respiratory specialist, infectious disease specialist, and haematologist throughout my life for hypogammaglobulinemia.

The IGIV treatment provided now is not at the optimum level. It is not regularly provided to help ward off infection. I work in an office environment where it is easy for infection to spread within the closed building environment. Cough, chest phlegm (I have bronchiectasis), and sinusitis were never resolved to the extent I no longer remember when I was free from these conditions. When IGIV was initially given prior to the economic crisis, it was given in larger dosages compared to now and was given every four weeks. That was the only time I had no cough, flu, sinusitis or chest phlegm recurring, thus enjoyed an improved quality of life.

Awareness

At the time of my diagnosis, I was in early secondary school and my parents are not educated. Until this day my family does not understand what I go through. In 2009 when I had severe pneumonia, I was not able to speak and no one was able to tell the doctor that I have hypogammaglobulinemia. After a few hours given oxygen in the emergency room, I asked for a paper and pen and wrote what I suffered from. Only then did I receive proper treatment. Since then I carry my medical book all the time. I researched my condition myself to understand more.

However, whenever I had infection I was often denied entry by the emergency department at the counter itself, saying I could go to the polyclinic instead for treatment.

Getting to hospital for infection with fever is always a challenge. As Ampang Hospital does not have outpatient services like GHKL, the only way to get in is through the emergency department. However, whenever I had infection I was often denied entry by the emergency department at the counter itself, saying I could go to the polyclinic instead for treatment. After numerous encounters like this, I just go to normal clinics outside whenever I get infection. At the clinic, it's difficult to make

doctors understand what I suffer from and sometimes I have to be on repeated visits to the clinic to get the right medicine. Vaccination is still a puzzle as some specialist doctors in Ampang Hospital have told me not to get vaccinated as my body is surviving on donated immune cells, thus making vaccines pointless. Some other doctors from the same hospital said I should get vaccination as it at least provides some layer of protection. Until now I have no idea if I should go for it or not.

Additional information

After stopping IGIV treatment due to the economic crisis and requirement for full payment, multiple pneumonia attacks caused severe lung damage.

Apart from the points provided above, I would like to provide additional views and share the challenges I face. When I was two years old (1983) I lost my left eyesight after sesame oil was applied to my eye when I had chicken pox. The family member who applied the sesame oil was unaware that it had expired. My eye was soon infected and a membrane-like layer covered my eyeball. I believe that my PID condition, which was not detected at that time also contributed to the loss of my sight. The left eye was then inoculated in 1988 at Tun Hussein Onn Eye Hospital.

After stopping IGIV treatment due to the economic crisis and requirement for full payment, multiple pneumonia attacks caused severe lung damage. In 2010, Ampang Hospital suggested I undergo a double lung and heart transplant and I was referred to Institut Perubatan Respiratori (IPR) given my age and status as NYHA class 3. After evaluation by Dr Ashari in IPR, it was decided that it was too risky to proceed with a transplant due to my immune disorder. Dr Ashari suggested to keep monitoring me and only decide on a transplant if my condition worsens. In 2010 it was discovered that I have Aortic Valve Regurgitation. Aortic valve replacement (AVR) was suggested and plans were made for the surgery to be performed at IJN.

Unfortunately, AVR was not done immediately as I had otitis media infection that time. IGIV treatment was also limited to every three months during the time due to global supply shortage. In January 2012, AVR was done after the ear infection resolved and IGIV given monthly again.

The point I'm trying to make is that irregular IGIV has caused recurring infections resulting in organ damage. The treatment which is not given at optimum level is still causing infections and slowly causing other organ damage, particularly to the lungs. It is crucial that IRT is given regularly at optimum level to improve quality of life.

I am also denied medical coverage by insurance companies, thus making it difficult to access healthcare services. The overwhelming crowd in public healthcare in recent years makes it difficult to get medical service. Worst case scenario, if in future I suffer a chronic illness like cancer, it will be very difficult to afford the treatment. As a matter of fact, I do have a medical card provided by my employer, however, it can only be used for accident coverage.

Coping with work is fairly challenging as well. Employers do not look favourably on employees who take frequent MCs because from their standpoint, it affects productivity. I initially had to hide my medical condition to get a job after recovering from heart surgery. I had to utilise my annual leave for my medical follow up and IGIV treatment. After proving my performance at work, I revealed to my employer my medical condition and the need to take MC for follow-ups. However, due to the number of MCs I take, I do not get optimum company benefits. My chances for promotion and bonus amount are also affected.

I would also like to highlight that due to lack of awareness and our culture that believes in superstition, many neglect the fact that what they're suffering from could be a medical condition requiring medical attention. I was brought to see many bomohs, astrologers and traditional medicinal practitioners (ayurveda, Chinese medicine, homeopathy, and so on). Likewise there could be others out there who are going through the same and trying to get help from such people. It is fortunate that all of us in MyPOPI are able to get information from the internet and other sources. But how about those who are illiterate or those who are not able to understand the information provided?

Name of patient: SOO SHENG JIE
Age: 20+

Name of parent: SOO AN HOCK@ AN HOCK BIN SOH
Age: 60

Diagnosis

My son, Soo Sheng Jie was diagnosed with autosomal recessive chronic granulomatous disease Type 1 (AR-CGD) on 2007. In January 2007, Sheng Jie suffered from pneumonia with high fever and chest pains. He was referred to Tawau General Hospital and a week later, Sabah Medical Centre, Kota Kinabalu for treatment. As paediatricians in both hospitals were unable to resolve his pneumonia, Sheng Jie was referred to the late Dr Amin Tai and the late Dr Haliza Mohd Shafie of Ampang Puteri Medical Centre, Kuala Lumpur (APM) a week later.

Based on images captured by x-ray and CT-scan, both Dr Amin Tai and Dr Haliza strongly suspected that the bacteria that caused the pneumonia was norcadia. At the same time, there were several ulcers in his mouth and culture results confirmed candida infection. Both infections were resolved in two weeks after applying antibiotics via intravenous infusion and antifungal medications aggressively. Both infections, which occurred concurrently, raised suspicions among the doctors about the condition of Sheng Jie's immune system. His blood was taken and sent to Institute Medical Research (IMR) Kuala Lumpur for investigation and the results showed low phagocyte levels.

Treatment

Dr Haliza consulted Dr Amir Hamzah Abdul Latiff, who was then attached to a local university, for proper CGD treatment and further investigation. With Dr Amir's assistance, Sheng Jie's blood was sent to Hong Kong and the results confirmed AR-CGD. Dr Amir also recommended a treatment regimen for Shen Jie consisting of septrin and intraconazole. While interferon-gamma (IFN-gamma) therapy subcutaneously is found to be very effective in infection prevention for CGD patients, it is unavailable in Malaysia. Dr Amir’s attempts to procure IFN-gamma through Pantai Medical Centre (PMC) ended up in vain. As all medications have side effects, a blood test must be performed during

Sheng Jie's bi-annual follow-up with Dr Amir.

I sincerely hope that the Ministry of Health can assist in IFN-gamma procurement from overseas and provide the same for all CGD patients in all government hospitals.

Care

Twelve months after Sheng Jie was diagnosed with AR-CGD, Dr Haliza assisted me in reaching out to physicians to take care of Sheng Jie once he reaches the age of nineteen. Regretfully, none of them have agreed to this (as previously mentioned, during that time Dr Amir was an associate professor at a local university). When both Dr Haliza and Dr Amin passed away in 2009, I encountered the problem of finding the right physician who could take care of Sheng Jie!

Since then, Sheng Jie encountered serious infections thrice and they couldn't be resolved in Tawau. He was referred to Dr Amir at PMC for the proper treatment. Fortunately, Dr Amir has agreed to take care of Sheng Jie at his clinic at PMC

Awareness

Sheng Jie and I are grateful to Dr Amir, the late Dr Haliza, and late Dr Amin Tai for rendering adequate information and advising us on the necessary measures for preventing infection. While my son is back home in Tawau, he is being taken care by Dr George Jinivon, who has carried out his own research and provides advice, including on vaccination.

Name of patient: STANISLAS SANJEEV MARTIN
Age: 27

Diagnosis

My name is Stanislas Sanjeev Martin and I'm the eldest among five siblings. I'm also the only surviving sibling suffering from PID (X-Linked agammaglobunemia). My mother suffered a miscarriage during her second pregnancy and my fourth brother passed away due to septicemia shock when he was 1 year and 6 months old. My two other siblings are perfectly fine.

I started having multiple infections when I was 2 years old. This included prolonged high fever, severe skin infection, severe ear infection (otitis media), puss would just be falling off my ear like water, and joints infection (septic arthritis). The doctors who treated me really didn't understand what was happening, they just treated every infection singularly without investigating the source of the infections. Every test they performed produced negative results. A typically healthy human being would not have multiple infections like I did or it wouldn't be as frequent.

I was diagnosed at 9 years old in 1998. It was after the death of my younger brother, which I have mentioned above. He died within 48 hours following a fall while playing in the field. He just had a small scratch but by midnight it became like a severe burn mark, and the whole arm turned blue-black so my parents rushed him to the hospital (Hospital Universiti Sains Malaysia Kota Bharu). He was diagnosed with gangrene and the doctors decided that his arm had to be amputated. So he was admitted and crying in pain the whole night. As morning arose, he slowly stopped crying and then his system slowly started to collapse. They tried to insert a ryles tube but his body rejected it, and he eventually passed away due to septicemia shock.

My ENT specialist, Dr Indhuharan, suspected something is wrong with my immune system after hearing the story of how my brother passed away. It's not normal for a tiny scratch to result in death in just 48 hours. So he immediately referred me to an immunologist based in Hospital Universiti Sains Malaysia (HUSM) Kota Bharu in Kelantan, which was non-other than Prof Lokman Noh

(foremost immunologist in Malaysia).

Prof Lokman diagnosed me with Bruton's agammaglobulinemia (X-Linked agammaglobulinemia). He told my mum that I was a lucky child as I had survived up to 9 years old, normally a person with this kind of disease will never live long without proper treatment. After that, my whole family was screened and our blood was sent to Finland. It took about three to six months for the results to come back. Surprisingly, it was not my mum who is the carrier (which is typically the case), I was born with it. My younger brother who died probably had the same condition.

Treatment

Following the diagnosis, Prof Lokman started me on IGIV at four vials (50mg per vial) once a month. After receiving this treatment my infection slowly started to subside, and after a year of undergoing the treatment, most of the infections stopped. I became like a normal person as I could go to school and was no longer frequently absent. I was active in sports and my studies showed improvement. I was so lucky that I met Prof Lokman on time and he diagnosed my disease correctly and recommended the correct treatment.

As I get older and as my body weight increases, the vials of IGIV would keep increasing. So from 4 vials I am now taking 24 vials. Thank God that HUSM Kota Bharu provides it for free. I am under the care of Prof Azlan, a haematologist. While I am given good care whenever I'm admitted to HUSM, I have been having breakthrough seizures. According to the neurologists, the seizures are not from the brain, but is probably due to the long term effects of IGIV treatment. Sometimes I will have palpitations during the immunoglobulin therapy.

Nowadays my peripheral vein is not sufficient enough to use for IGIV, so left with no choice they have to set my line at all my main veins, femoral, and neck. During the last few IGIV treatments, I have been suffering from DVT (Deep Vein Thrombosis) on the thigh and downwards, due to multiple needle insertions. As a result, my whole leg becomes swollen. Recently, my leg swelled like a balloon and I was unable to move or even carry the leg. So now I've decided to do insertion through chemo port.

Care

I was transitioned from paediatric to adult ward when I was 15 years old. After Prof Lokman left HUSM he handed over my case to Prof Nik Zainal who was at the time, a medical officer in the paediatric ward. The main issue is I don't have a clinically trained immunologist to monitor me. Each time I get admitted I see different doctors and I have to explain my condition to them–my file is so thick now with many volumes! Even certain specialists don't know what PID is.

I only meet Prof Azlan (whom I mentioned earlier) from haematology in the clinic once in a while as he is not a specialist in immunology. Maybe he is just taking care of me out of pity, I don't know.

Awareness

When my parents were told that I have this rare disease, they had no idea how this could happen, until along with some other family members, they did their own research on the internet. Only then, did they have a better understanding. As I grew up, I did my own readings to know more about the disease I have. I have also encountered many doctors, specialists, and medical officers who have been practising medicine for very long time but have never come across this kind of rare disease.

For now I have to be in Kota Bharu, Kelantan, I can't move away from here because HUSM is the only hospital that is giving me the medication I need for free. I wish the medication was available in all government hospitals nationwide for free. I also hope that the government can also change the mode of treatment from IGIV to IGSC, which involves receiving immunoglobulin subcutaneously. It hasn't been an easy journey for me and my parents enduring all the pain and difficulties that come with this disease. I am sure that most PID patients have gone through the same or even worse.

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Appendix 11

Name of patient: YUSUFF BIN ARIFF

Name of parent: ARIFF

Diagnosis

We realised that something was wrong when Yusuff had to be hospitalised for a third time at Sultanah Bahiyah Hospital with high fever and suspected pneumonia in July, 2014. It was then that the doctor at the hospital suspected that Yusuff might have an immune problem. Yusuff was sent to HKL for further investigation. That's where we met Prof Intan for the first time. She visits HKL once a month and luckily she came to visit us in the paediatric ward. She advised us to take the PID test at the Institute of Medical Research (IMR). We then asked for a transfer to Serdang Hospital so that Prof Intan can monitor Yusuff easily as she is based there. At Serdang Hospital, Yusuff was diagnosed with chronic granulomatous disease (*CGD*). It took around five months from the time he was first warded for Yusuff to receive this diagnosis. Prior to that, he was give multiple antibiotics and was even suspected of having tuberculosis at one point.

Treatment

Yusuff is currently on once a day intake of Itraconazole and twice intake of Bactrim three times a week. Prof Intan has also suggested getting a bone marrow transplant. Yusuff spends his time at home cared by me and once in a while is sent to kindergarten to mix around. We don't go to crowded places such as night markets, birthday parties or weddings.

Care

We follow the medication guidelines, clean the house more often, avoid crowded places and avoid unhealthy people.

Awareness

Not much information was given, instead we had to go looking on the internet about the disease. We found out that there are a lot more people in the world having the same problem.

Not much information was given, instead we had to go looking on the internet about the disease. We found out that there are a lot more people in the world having the same problem. In the beginning we had to explain to the GP about live vaccinations because they are not aware of the disease. Later on we requested a letter from Serdang Hospital to tell the GP not to give live vaccinations to our child and they just followed the letter of recommendation.

Additional information

I was once a weekend husband and father to my lovely wife and son. They live in Changlun, Kedah and I live in Puchong, Selangor. My job at the time was as an IT specialist in a public listed IT company in Subang Jaya but I was in the middle of changing jobs. My wife is a lecturer in Perlis. I only got the opportunity to spend time with them five to six days in a month.

When Yusuff was 2 months old, he was admitted to Sultanah Bahiyah Hospital because of high fever. The doctor suspected that his digestion tube was infected by bacteria. He was given an IV antibiotic and admitted for nine days.

He was 7 month old and the doctors did not know what he was suffering from…The doctor gave around 13 types of IV antibiotics and all failed. The high fever kept on returning after three to four days.

Yusuff during his first admission at Sultanah Bahiyah Hospital

A few weeks after Yusuff was discharged from the hospital, I got a new job in a multinational IT company in Cyberjaya where I worked for around three to four months before resigning in search of other opportunities. At that time, Yusuff fell sick again with high fever and was admitted to Sultanah Bahiyah Hopital for around 45 days. He was 7 months old and the doctors did not know what he was suffering from. His blood culture results did not show anything. The doctor gave around 13 types of IV antibiotics and all failed. The high fever kept on returning after three to four days. He was referred to HKL for further treatment. My wife had to take two months of unpaid leave to take care of Yusuff and had to postpone her PhD thesis. While in HKL, where he was admitted for around 20 days, Yusuff showed improvement.

After Yusuff was discharged from HKL, I got a job offer in Bukit Damansara and my wife started to work again after a long period of unpaid leave. Then, Yusuff was admitted to Sultanah Bahiyah for the third time with high fever. This time I postponed joining the new company and took care of Yusuff in the hospital. Yusuff was admitted for around 20 days and the doctors in Hospital Sultanah Bahiyah suspected that Yusuff was having a problem with his immune system. The doctors asked us if our family had any history of immunodeficiency and my wife told the doctors that her second sister had children that might have the same problem as Yusuff. The doctors had to trace back the

log book in the old hospital and found out that my sister-in-law's son was diagnosed with CGD but no specific treatment was given. The doctors recommended that Yusuff seek treatment from a specialist and he was referred to HKL for the second time.

The doctors in HKL thought that Yusuff had tuberculosis and would need to take anti-TB medication. During that time, Prof Intan from Serdang Hospital was in HKL for her monthly routine and suggested that Yusuff might have a problem with his immune system. I requested that my son be transferred to Serdang Hospital so that it is easier for Prof Intan to monitor him.

In Serdang Hospital, Yusuff was diagnosed with CGD, which is a Primary Immunodeficiency disease and was admitted for 16 days. He was given medication for his CGD and also anti-TB medication for one year. From that point on, I decided not to work anymore and instead, stay at home while my wife continues working on her PhD thesis.

While in Serdang Hospital where Yusuff was diagnosed with CGD

Yusuff had been in and out of the hospital frequently but nowadays, he seldom has to stay in the hospital. We have learned the dos and don'ts of caring for him given his condition. And we are still learning every day.

Yusuff nowadays, very active

PID is not a well-known disease like leukemia. Doctors did not know how to treat him and we had many tough days in the hospital, praying that one day Yusuff will recover.

Name of patient: ISKANDAR B. SYAHLIZAN
Age: 6

Name of parents: SITI AMINAH BT. AMIR and SYAHLIZAN B. SAIMIN

Diagnosis

Since birth Iskandar health was affected with infections and flu. The worst episode was when he was 5 months old, he was admitted to Hospital Sultan Aminah, Johor and then transferred to Paediatric Institute at HKL because of bronchopneumonia. He was in and out of the hospitals during the period of December 2011 till August 2012 for series of childhood infectious diseases whereby some required intensive care and high dependency and were referred to numbers of specialist especially respiratory, cardiothoracic just to name a few. Iskandar was suspected as Hyper IGM Syndrome when referred to immunologist team during his admission to hospital for persistent diarrhoea in 22nd August 2012 and blood sample was taken for further test.

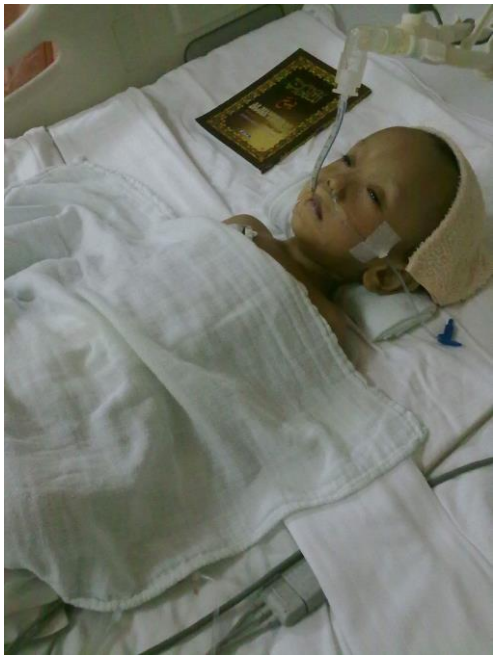
It took almost 1 year to receive the correct diagnosis, which is Hyper IGM Syndrome. Some specialist diagnose him with Interstitial Lung Disease and Loffler's Syndrome.

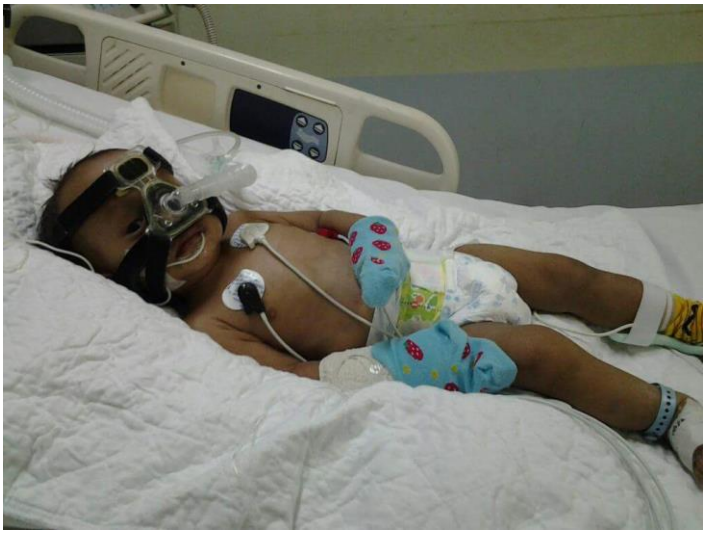
Treatment

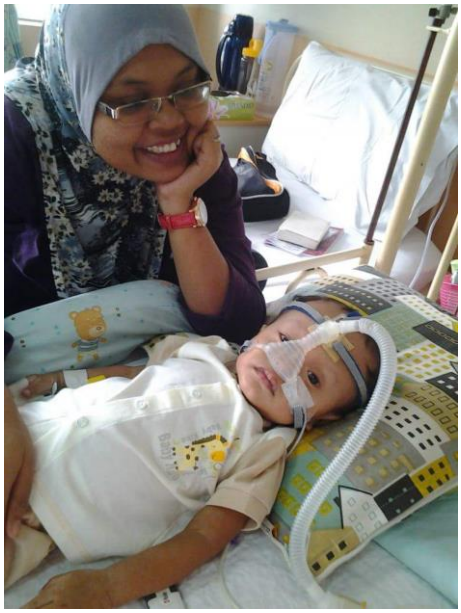
He has to undergo IGIV every 3 weekly and prescribed with Bactrim after the right diagnostic. Initial treatment is tough for us as family because Iskandar needs to be admitted to the ward to get his IVIG through cannula insertion after many attempts and it is traumatic for him and us as parents. He is now being treated with IVIG through chemo port but we have to purchase the needles and tubing on our own. There have been adverse reaction or side effects during and after the infusion; he was prescribed with premedication of Hydrochoq.

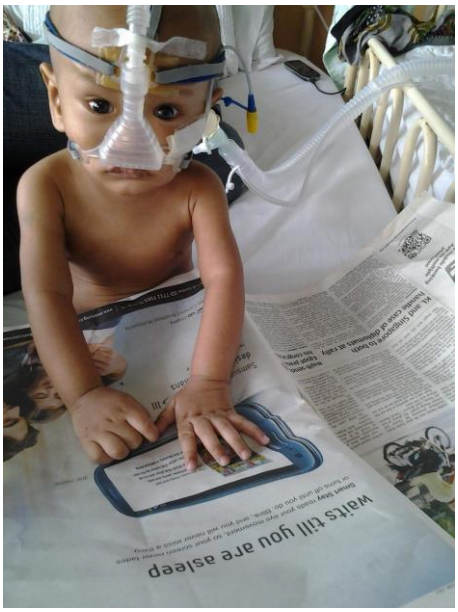
Awareness

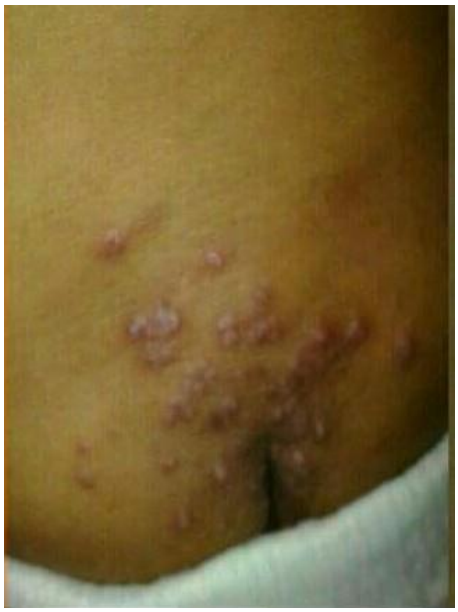
General practitioners are clueless about Iskandar diagnosis and insisted that I ask Immunologist to explain to us. In many cases we encountered doctors at general clinics are ignorant of my son primary immunodeficiency condition and they don't pay enough attention and take no extra precautions to prevent unnecessary risk that might affect his health especially on giving live vaccination to my son.








Waits till you are asleep



Acknowledgements

The authors of this white paper would like to extend their gratitude to the Malaysian Patient Organisation for Primary Immunodeficiencies (MyPOPI) for their contribution and assistance. The recommendations developed in this paper have been greatly informed by the invaluable insights of the MyPOPI members and the personal experiences they have generously shared. Bruce Lim, president of the MyPOPI, was instrumental in developing the questionnaire and compiling the recollections and stories of patients affected by PID. Additionally, this white paper has tremendously benefitted from the guidance and support of the International Patient Organisation for Primary Immunodeficiencies (IPOPI). Their thoughtful suggestions, feedback, and expertise have strengthened the contents of this paper and the message we aim to communicate through it. Thank you Najua Ismail for her editorial and layout contributions, and Fong Li-Mei for providing assistance with graphics.

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