MPN Charity Dinner, 11 August 2018 - Jolanda Visser's speech

“When Trevor Holst, last year, said he wanted to help support by raising funds and create more awareness for MPNs, I never imagined it would be in this fashion.

So here we are! When we put the run sheet together for tonight, I decided I only need 15 minutes to give you a brief introduction to MPNs. But now I look around I realize I need at least 15 minutes to thank you. I see friends surrounding me and am overwhelmed by your support. Each one of you here tonight has made this event possible. Without your support and generosity, we would not be gathered here tonight. So I would like to thank you and all the sponsors from the bottom of my heart.

So MPNs? That is why we are here. I have received strict instructions from my husband who reminded me that we are here to have fun and we are not here to listen to technical or medical jargon. However, as you are all here to support MPN Research, it is appropriate to give you some insight to MPNs and what it is like to live with an MPN. I am not a medical expert and I also do not want to give you the impression that I know all there is to know about MPNs. However, what I am a specialist in, is living with Essential Thrombocythaemia. Let’s call it ET to keep it simple.

ET is part of a progressive group of blood cancers called Myeloproliferative Neoplasms. To make it easier, we refer to this as MPN. This means that the blood cell production in the bone marrow is affected and cells grow and reproduce abnormally. The abnormal bone marrow stem cells produce excess numbers of one or more types of blood, such as red cells, white cells and/ or platelets. These abnormal cells cannot function properly and can cause serious health problems. The increased numbers can change the thickness of the blood and increase the risk of thrombosis also called clotting. Strangely due to the abnormal functioning, it can also cause bleeding. This is what happened in my case, too many blood platelets. I will get back to this shortly.

MPNs result from a change, or mutation, in the DNA, a persons genetic code. MPNs can remain stable for years and progress gradually over time. Some patients may develop additional abnormalities, such as acute leukaemia or transformation to myelofibrosis, where the bone marrow is scarred and unable to produce blood cells. These two are the ones an MPN patient fears most. MPN patients are also at a higher risk for secondary cancer.

There are three classic MPNs, known as ET – Essential Thrombocythaemia (too many platelets), PV – Polycythaemia Vera (too many blood cells), MF – Myelofibrosis (scarring of bone marrow).

Ok that was a tiny bit of MPN education. So how and when did I get introduced to MPNs? Well my MPN journey started in 2003, when I was 33 years old. I was accidentally diagnosed, which means that I had no symptoms but as a result of a blood test that was taken for a skin issue I struggled with, they discovered an elevated platelet count. A repeat

blood test a month later showed that the count had increased again and I was subsequently referred to a haematologist, who then ordered a bone marrow biopsy. The result was a conclusive ET, too many blood platelets which, have the risk to make my blood clot.
So what do you do with this information? What does it mean? Well interestingly my haematologist didn't really know either. MPNs are often diagnosed amongst older people, like 65 years and over. So there I was, 33 years old and I remember thinking, how will this work out long term? The haematologist told me to start taking a daily aspirin to reduce the risk of clotting. I thought great, I've moved into the 'mature aged' bracket. My dad was in his early sixties at the time and his doctor also recommended he should take a daily aspirin. However, I quickly moved on from my diagnosis. I had no symptoms, so I did not worry about it. Life had not changed and I was too busy to be worrying about ET and what it meant. I did google it, but it did not make much sense to me, so I figured what was the point thinking about it. Occasionally I would worry when I had to have a blood test and the results showed the platelets steadily going up after each test.
But then, things started changing in 2006 when I ended up at the Flinders Emergency department with stroke like symptoms. It was a scary episode in a chapter of our life. But what was worse, it was after this event that I started experiencing actual MPN related symptoms. The symptoms consisted of a continuous headache, extreme fatigue, dizzy spells, and an occasional blackout. This happened once on a platform at a train station. It was the start of my life changing as I had known it up until then. I started losing my confidence and was too scared to go out on my own.

In 2009, I had enough of being in pain and started treatment in the form of a daily chemo tablet. It took a few days of getting used to, however, this managed to reduce the symptoms somewhat. The dizzy spells went away and I experienced an increase in energy levels. And although it did not eliminate the headaches, the pain became manageable and my quality of life improved.
Unfortunately, in 2013, I had a second trip to Flinders Emergency, but this time the symptoms were worse and I temporarily lost sight in one eye. I was placed on the stroke ward for observation. After 3 days I went home, but life drastically changed after this. Before this event I was living a very busy8tine I could cope with. My headache had increased and I was in constant pain. I was very tired and had ongoing issues with my vision and bone pains. My chemo dosage was increased and other medication was added to my daily intake to just try and manage the continuous pain. I was in bed by 7pm and hoped I fall asleep quickly so that I did not have to deal with the pain. But, I would wake from the pain and struggled to fall back asleep again. It was a horrible time and living life was a struggle. I started isolating myself from friends, as I could not cope with myself. We would not plan anything ahead of time, because the chance I would need to cancel was big. This not only affected me, but also my husband, Craig. I am truly blessed to have such a loving, caring and understanding husband. Looking back at this time of our lives, I realised how difficult it was for him to see his wife in so much pain and not being able to do anything to make things better. It was difficult for him to fully understand what this condition was all about and what the future would look like.
Which, for now I would like to make a little side-step. For the many years I lived with ET, I

was mainly in denial about the seriousness of it. If I cared too much it would impact my life too, so ignoring it was better for me. Craig also didn't know much, partly because of my attitude but also because there is so little known and reliable information available. After this event, it became evident things were going to change and we both needed to accept it and deal with it. At the start of 2014, the Leukaemia Foundation hosted a blood cancer conference in Adelaide and MPNs would be represented. So we both attended and it was only then that Craig started to understand the seriousness of my situation. What the risks were and how progress could occur. All this time he could see I was in pain but only made the connection between the two after he was better informed during the conference. This information was a game changer.

It was also at this time that I started researching everything I could find on MPNs, progression and symptoms. I found an Australian email support group and could rely on the Leukaemia Foundation for support. By being in contact with other patients and participating in MPN specific phone support sessions, I learned that I wasn't the only person who was struggling with these symptoms, but many other MPN patients around the country had similar experiences. Some of them are here with us tonight. Slowly but surely, my MPN was starting to make more sense and I realised that unless they find a cure, my ET will continue to progress. Through the MPN support community I came in contact with a few passionate patients who all believed that we could do something to help improve the lives of existing and newly diagnosed MPN patients. We had a few Skype meetings and at one of these meetings, I was introduced to a young mum who had a very young 18 month old daughter who was diagnosed with ET. It broke my heart, as I knew how much I struggled with my symptoms so how would the ET affect this girl. I was concerned if she was in as much pain as I was and I struggled to make any sense out of it. It was this defining moment that I made the decision I needed to do something to help make a difference and try change her prognosis.

So with 5 of us patients, we partnered with the Leukaemia Foundation of Australia and in 2015 we established the MPN Alliance Australia. We since gained a few more members and we now have a core group of 7 people who think of and execute initiatives that will benefit the MPN community. We do not get any financial support from any government organisation or the Leukaemia Foundation and all our initiatives are funded through our own fundraising efforts. We all have useful skills and by combining these skills, we have enabled some great achievements in the past 3 years.
Through my involvement with the MPN AA and the fact that I suffer from ET, I have met some amazing people in Australia and around the world."