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Immune Deficiencies Foundation Australia

PPTA

Plasma Protein Forum, Washington DC, June 12-13 2018

12/06/2018

VIDEO INTERVIEW SUMMARY

During the conference I was interviewed about:

- the immunoglobulin (Ig) situation in Australia
- my thoughts about paid blood donations
- How does the world develop consistent planning around Ig?
- How are patient organisations supported?

My comments included:

1. **Australia is the 2nd highest consumption per capita of Ig in the world (USA no 1).** Despite this fact:
    a. In contrast to the USA and most other countries in Europe, rather than a tax system on I suppliers, we use a 4-year tender system to determine who provides Ig in Australia. The consequences of this are:
        i. CHOICE of product for patients - is determined by the NBA, not the immunologist in consultation with the patient.
        ii. CONTINUITY OF PRODUCT - This choice is changed every 4 years, regardless of specialist choice and patient suitability
        iii. PRODUCT SUITABILITY - Ig products are manufactured differently. Often one particular brand really suits a patient (less infections, hospitalisations, better blood levels). Although a patient may be responsive to one Ig product, they are not on that product for life. If that product does not make the next tender, the patient is just changed to one of the tender products (which may not suit them)
    b. Ig USE – in Australia the majority of Ig is used for neurology patients, then immunology patients. In most other countries around the world this is reversed and the most Ig use is for immunology patients.
    c. ACCESS TO TREATMENT – The NBA reviews the criteria for Ig use every 3-4 years. Every review sees less immunology patients receiving Ig. Now Bloodstar has been implemented, this is the tool for the new criteria .. more patients needing Ig will not receive it.
    d. HOME TREATMENT – In other countries around the world, subcutaneous immunoglobulin (SCIg) treatment at home is the major form of treatment. In Australia, access to SCIg has been restricted due to the rules set by the NBA for hospitals to introduce the program. Hospitals are reimbursed for IVIg patients, but not SCIg patients so there is no incentive for a SCIg program to be

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implemented. Patients are being charged a dispensing fee of approx. $130 to claim their SCIg from the hospital pharmacy. They also need to buy a pump ($4,500) and consumables.

e. PATIENT ORGANISATION not SUPPORTED BY THE GOVERNMENT – IDFA is a large patient organisation supporting people affected by immune deficiencies (Primary and Secondary). IDFA is not government funded. They should be supported to continue their work and be able to reach ALL patients with immune deficiencies in Australia.

2. PAID Blood donations

a. We need to realise that the world is not self sufficient on voluntary blood donations
b. Most countries in the world have both paid and donated blood. Donated blood is usually through government collection centres and paid blood is through plasma pharmaceutical companies who have collection centres and often a plasma processing plant in that country.
c. Our situation is that our national supplier CSL is the only plasma fractionation centre in Australia, so there is no variety of fractionation centres
d. We have a strong history of "donating" blood in Australia, however most Australians are astounded to find out we import 44%. I do believe most Australians would see this as a "repugnant transaction". ***A repugnant transaction is defined as " x + $ is repugnant even when x alone isn't" .***– that is, if some people want to engage in a transaction and others don't think they should be allowed to (even if the transaction doesn't cause any easily measured harm).
    i. examples include:
        1. Same sex marriage
        2. Surrogacy
        3. Donating an organ
        4. Claiming cadavers for medical science
        5. Lending money for interest (was once illegal)
e. Often there is a belief (thanks to media) that paid blood donations are tainted. However, blood is screened for viral and other impurities on collection and further screened at the fractionation plant and during processing. Any tainted blood is destroyed.
f. People may think that "donors" will no longer donate if plasma collection is reimbursed, however there is no good evidence that paid plasma negatively affects unpaid collection.

3. How does the world develop consistent planning around immunoglobulin supply and demand?

In a united world, it would be good to see:

a. Establish world standards for:
    i. Screening of donors
    ii. Collection

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iii. Manufacturing of plasma products with an emphasis on safety and quality

b. Establish world policies, procedures and processes for:
   i. Plasma quality management
      1. Plasma collection
      2. Plasma manufacturing
      3. Plasma safety
   ii. Plasma sufficiency
   iii. Plasma compliance
   iv. Risk management
      1. Conduct inspections of plasma collection centres and testing labs
      2. Follow a universal compliance program
c. Establish world standards on trade
d. Establish an international government reimbursement practice that reflects the unique nature of plasma protein therapies;
e. Educating all stakeholders about the value of plasma therapies
f. Establish an effective international communication platform to promote blood safety information exchange

4. Markets need social support to function well

a. The role of the patient organisation in plasma governance is important. Patient organisations can supply statistical data on a variety of disease implications. They can also raise awareness, promote and support the role of plasma therapies in the community.

b. Plasma is not a simple commodity, it is necessary for patient survival, as it becomes part of a patients' immune system, increasing their immunoglobulin trough levels, reducing their infections, reducing their hospitalisations and increasing their quality of life.

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