

## Submission to Senate re The inquiry into the operation and effectiveness of patient Assisted travel Schemes (PATs)

As an accommodation facility for 23 families attached to Children's Hospital at Westmead we would like to provide the following information to the Senate inquiry into the effectiveness of the Patient Assisted Travel Schemes. We accommodate around 500 families of the most seriously ill children in the State of NSW and other States.

Our families come mostly from rural NSW; however we deal with Northern Territory, Western Australia, Queensland, ACT and overseas families. This is due to the treatments offered only by the Children's Hospital Westmead. E.g. liver transplant

Our statistics in this House show we have had:

No. of Families	IPTAAS NSW	WA	QLD	ACT	TAS	NT	*KIN Central Coast	Self cash	Over seas
1Jan 2006 31 Dec 2006	244	1	9	19	4	2	25	42	10
1 Jan 2007 30 April 2007	140	1	4	11	4	1	12	15	6

\*KIN is an organization called Kids in Need set up to pay the accommodation shortfall of children in their area that are NOT covered by IPTAAS on the Central Coast. These elderly ladies many of whom have had sick children and grandchildren have street stalls to raise money for these families accommodation. They do not ask for signed statements from doctors and IPTAAS offices.

For the families of children newly diagnosed with cancer (80% of our clients) the process of filling out forms, understanding how to claim and where to lodge these forms becomes an onerous task. Many do not have time to devote and our staff assists with the filling out of forms for both the illiterate and stressed parents. Whilst they are required by IPTAAS to pay the first 2 nights at \$42 a night, (as a Charity we waive this occasionally as we know we will never receive the payment and do not want to add further burden to these parents nor have the staff or resources to chase up) the parents then have to fill in the forms to claim the \$33 a night, which in turn comes to us to cover 50% of their stay.

The actual cost to Ronald Mc Donald House Westmead is \$65 a night per room, to keep a standard of accommodation that is one of a "home away from home" and as a charity we have to fundraise to cover the cost that IPTAAS does not.

The added financial costs to these families is horrendous and if you have the unfortunate luck to have a child diagnosed with cancer your out of pocket expenses is in the thousands of dollars.

In the past five years I have fundraised to relieve this financial burden, While staying here at Ronald Mc Donald House Westmead we provide washing machines and dryers so that the cost of laundry is free. We provide clothing, breakfast cereals, milk, bread and other food items to the families, to reduce their day to day living costs.

For families who do not qualify for the healthcare card (and cannot bulk bill) because they have their own business they are expected to pay up front for all accommodation before they get it back from IPTAAS.

Many mothers live here all week with a child with cancer while father works at home. They need to have that emotional support on the weekends from their partners that we cannot offer.

We provide petrol money on an adhoc basis (only because a family donates for this and it runs out quickly) to families who want to have the emotional support of a partner – average cost for a father to visit Sydney on a weekend is \$100.

Many of the cars are not roadworthy, usually not reliable for long distance travel, bald tyres, no registration – all costs to the families.

This is for the families who have a car.

If the family has to use public transport it becomes a nightmare for them. We take them to the train or bus station (we have an arrangement with Greyhound where they can travel free of charge) with luggage and wheelchairs, sometimes one suitcase is for the medication and healthcare needs. They somehow manage to travel with sick children to their home town. I know in some cases, particularly for remote indigenous families they opt not to bring their child for treatment because the difficulties seem insurmountable.

### **Continuing IPTAAS (NSW) issues for families staying at Ronald Mc Donald House Westmead**

- ♥ It sometimes takes six months to get paid once a family leaves the House, which can often mean we have outstanding debtors for families as far back as 9 months. As we tend to have a lot of long term families, this can mean we often have an excessive outstanding debtors list.
- ♥ At least more than half of the 23 families who stay at the House are here for stretches of time that extend over 3-4 months.
- ♥ Once bulk billing has been approved, it would make far more sense to be able to send the invoices monthly rather than have to hang on to them until the family actually leaves.
- ♥ Many of our clients find it all too difficult. Just another lot of paperwork such as Medicare and Centrelink. As they do not get the full rebate there is no real incentive to fill in and get money back. Some families just do not lodge the forms even when we provide a stamped addressed envelope.
- ♥ We wait long periods for fees and cannot rely solely on the IPTAAS funds. We have seen a larger percentage of waived fees in the past 2 years

- ♥ The role of charities that provide the accommodation and other assistance has increased and whilst there is a so called travel allowance it does not cover many issues that families face.
- ♥ Knowledge is required of where every town in NSW is located in terms of the 6 IPTAAS offices. The change of these office boundaries has also been an issue of which office to contact.
- ♥ Dealings with other State systems and people in the offices Western Australia PATS and ACT in regards to quick and efficient payments of invoices and politeness is noticeably different to NSW

The fuel rebate is a joke. Can you really get from ACT and return for \$40? Maybe the realities of petrol costs go over the heads of politicians who have all their travel costs provided. I extend an invitation for anyone on the Committee to visit our facility and talk to the families.

**Adrienne Pearson**  
**General Manager**  
**Ronald Mc Donald House Westmead**