

## Collated Comments from Parents

I have a lot of direct interaction with families whether it be face to face or via phone or social media. As I support rural patients while they are in Brisbane for medical reasons I have been made aware of these issues from Day 1 of opening. There are many other concerns I can include in this document however, I felt it necessary just to keep it as brief as possible but also at the same time present the different scenarios.

I will also forward to you a copy of the email that I had sent out to both Lawrence Springborg who was the Health Minister at time of opening and Jo-Ann Miller who was the Shadow Health Minister, that email was sent after speaking with the Director General's office expressing my concerns from parents on week 1.

To this day the only response I have had personally was a confirmation the email was received and a message on voice mail saying that Qhealth would be in touch. However the follow up provided by the Health Minister and QCH executives was to claim "teething problems" with no follow up to any of the concerns mentioned.

Thanks for your time.

Justine Christerson

Founder of Breaking down the Barriers for Rural Patients in City Hospitals Brisbane

Subject Line: Our Meeting with the Health Minister about LCCH

Dear (membername)

On Thursday morning (yesterday) Together representatives met with the Minister for Health about our significant concerns regarding the opening and operation of our hospital.

We have all raised issues of wanting better for patients and their families but also importantly for **you, your colleagues and your families.**

The Minister listened carefully and his Chief of Staff took extensive notes.

We didn't get an immediate action plan from the Minister today but we are pleased that he spent double the allotted time because what your colleagues had to say was compelling.

We expect some answers to our requests for urgent action soon.

As the staff who have been keeping to together and keeping it going in the face of incredibly difficulties you need to know what's going to happen next.

We all need some help, and some significant action.

At the meeting each of the 4 staff representatives - 2 senior doctors, an administrative officer and a health practitioner talked about the significant issues they (and you) are facing in delivering care for patients and how they are feeling about working at Lady Cilento.

They talked about the urgent need to address staff morale and to feel valued. You need to know there is a light at the end of the tunnel because too many people are already leaving or looking for other work.

They spoke about the urgent issues that need to be addressed to do with patient flow, work spaces, amenities, IT resources and issues with Medirest and that they will only be fixed if staff are encouraged to stay and keep doing the amazing job they have been doing despite big challenges.

At the meeting with the Minister was also the Health Service Chief Executive Fionnagh Dougan and EDMS Dr John Wakefield.

Ms Dougan and Dr Wakefield acknowledged what the Together representatives were saying and outlined that they wanted to work on these issues too.

We were all saying to the Health Minister that this was not a problem for Children's Health Queensland alone however, this was going to require additional support and resources, and acknowledgement from the Minister.

We asked for an inquiry in to what had occurred to date, we asked for an apology to staff who have

delivered in exceptionally difficult circumstances, we asked for additional funding to be delivered to assist in recruiting more and retaining existing staff and we also handed over a list of concerns from the parents of patients which they had asked us to do.


We will now be following up again locally. James Douglas who is your Together organiser is visiting the Hospital regularly and will be working with members in individual teams to progress our issues.

We want to see big changes but given our meeting was just yesterday we know we may not get an immediate response from the Minister.

We will continue to raise issues with the management team in the mean time because if we don't keep pushing we won't achieve the change that needs to happen.

You deserve better.

Thank you for all you are doing, we will be in touch as soon as we hear anything, in the mean time please contact James about any matters to be progressed in your teams -

 [@together.org.au](mailto:_____@together.org.au)

Alex

These are copies of concerns that have been brought to my attention just this week, from parents whose children are to attend or are currently attending LCCH. These issues are concerning and highlight problems with delays in appointments, surgery or cancelled appointments and surgeries. Delays on treatment and appointments is detrimental to a child's health for some, the other concern is that these are only from parents who are now aware there was an issue with scheduling appointments and transferring of records, sadly there are many who are patiently waiting for an appointment and are not aware there is no appointment scheduled, which again is very concerning. (this is just one week of 13 weeks of complaints, this week was used as a summary of examples of concerns since the opening of the hospital)

Please note the colour changes indicate separate parent concerns and are quoted from the complaints I have permission to share.

"I am a very frustrated parent. 5 phone calls with zero emails or calls back, 1 letter of correspondence saying I need to call to confirm my details in order to get an appointment and still nothing. Have been waiting since June last year.

He is at risk of losing his eyesight. Is a category 2 and still nothing."

"Personally we have had our scripts for feeds cancelled because we missed a dietician appoint that we didn't even know about, we have been offered surgery for the very next day ( which we couldn't possibly make it to) when we were told that there would be a minimum of Two weeks written notice.

We have been given No notice of follow up appointments or surgery even though our son has been waiting for a year to date for his procedures & he has a life threatening rare disease"

We are having a major problem. PICU has no freezer for breast milk. It's been stored on level 9 lost some smashed some . Now level 9 just said they will not take any more. What are we meant to do? Spoke to boss people they have now said they can store a little bit in 10b. But what do we do once they run out of room? ATM she is on a special formula for a couple of days then back on breast milk. But I have to keep expressing and they told me to keep freezing as its important.

"I have 2 children with complex medical diagnosis's. My 13 year old spent over 20 weeks in hospital last year and sees 8 specialists, she is also fed via gastrostomy button. My youngest daughter is almost 4 and she also has a feeding button and multiple conditions and sees 14 specialists.

Since LCCH opened I have not had any contact from them other than 1 overnight stay with my 13 year old with an infection in her button. Even with this small amount of contact we have not been informed or been able to find out who or how to contact someone in the event something goes wrong with the girls buttons. I have also not been able to get a call back from the nutrition dept in regards to my daughters script for her formula from the outsourced company has not been updated so I can not get her feeding supplies. Both girls are overdue to see some of their specialist but the outpatients dept have told me I will be informed when an appointment is made. One of these specialists is cardiology so fairly important.

I was told we could get connected care as we are also rural patients and have to travel for treatment, but we were declined even though we meet the stated criteria.

Neither girls have any outpatient appointments listed.

According to LCCH outpatients dept one child does not exist on their system. Her name and date of birth does not register with a ur number. The other has a ur but the only records in her files are from her 1 night stay at LCCH, no history from rch

They told me to go to gp to get new patient referrals for all one child's specialists. She sees 9 (Cardiologist, gastroenterology, endocrinology, ENT, Rheumatologist, respiratory)"

"When we attended five appointments in February they couldn't find my son's file until the last appointment."

"Both mackay hospital and prince charles centre confirmed referrals being received and that we are a category 2. Cat 1 patients wait 6 weeks supposedly and we wait 9 months plus for just an appointment time still yet to be disclosed to us. ophthalmology referral was put in before prince charles but they confirmed my son's need for corrective surgery as he maybe experiencing double vision and in turn sooner or later his brain will go yes I am working too hard now left eye shut down"

parent arrived to an appointment and told no patient records avail. Then changes that have been made to child's circumstances at that appointment were not recorded! No record of changes made to treatment!

"we recently had two appointments, first was ok and the second was cancelled without notice, tried to tell them this is why the doctor had organised the appointment as it was a new drug he was on and this was to be the review to continue with it, Next visit we could get with him was 1st April, so he wouldn't have had his injections for almost 2 months"

"My son had his tonsils, adenoids and grommets done at the end of January, was an absolute mess in recovery but wasn't called until he stopped breathing, he recovered thankfully. On discharge I was told I would receive an appointment to have a check up 3-4 after discharge, I asked a few times that the hospital would contact me and was assured they would, I waited 3 weeks with no contact, upon ringing I was told they don't offer follow up appointments instead a nurse calls, asks if child is fine and if not then an appointment is offered and was told someone would call in the next few days, well that was weeks ago and thankfully my gp has cleared my son of any issues and reassured me that he has healed well. This is on top of the fact the hospital rang in January asking my hubby if our boy still needed a gastro appointment as we have been waiting 12 months, after he assured her we still needed it we were told that they would then send out the next available appointment for him, upon ringing about ent issues I queried them about the gastro appointment we never received in the mail, I was told they didn't even have an appointment for him and that he is still a fair way down the waiting lists. So disappointed with the new hospital and how it's running I was happy to have the 2 different hospitals, at least we knew what was really going on with them."

"We've only had minor issues. We got an appointment letter (can't remember the clinic) and on the day I thought I'd just ring and double check (as it wasn't long after opening). They had no record of the appointment and said disregard the letter. So glad I called! And on a recent unexpected overnight stay in the whole hospital there wasn't one suppository?? (When my son is constipated which is frequently he has terrible muscle spasms.) The nurse called all the other wards and apparently no one had any. Also a lot of

the staff seem to have no idea where certain supplies are kept. Also the day surgery ward sucks!! It's one giant room with 28 beds."

"My daughter had a small op there Monday a couple of weeks ago and had to go over to Mater on the Tuesday for an MRI. Now, LCCH are saying to my dr's secretary that she didn't attend the MRI and they don't have a copy of it - even though the results are in the computer system and can be viewed here at the Base in Mackay."

"My daughter was meant to be having day surgery in February to remove her umbilical hernia and I still haven't heard anything I did call and they said she should receive a date sometime after March 1 ??? That could mean anything ... Maybe I should call back now that March 1 has passed? just been on the phone only to be told it could be up to 12 months away, I was meant to be in February March and now all of the sudden it's up to 12 months away "

"Called yesterday and I was well past the category time and I not even there."

"My friend rang up as no letter nothing they had sent it to her address from 5 years ago"

"I called and found out about a referral put in November they did have it and it's a cat 2 which now might not be seen for 9 months use to be 3months but person I spoke to was very helpful and try to get her seen next time I am down"

"The fact that rural and remote patients are given so little notice about specialist appointments. 1 month or 4 weeks is not enough notice for a 2000 klm trip when it takes a week for the letter to arrive to the patient in the first place. So if escort needs to organise other children to be cared for and take time off work they are generally only giving their employers approximately a fortnight's notice."

I rang LCCH today as I am expecting a letter for miss 14 any day now, regarding a Ophthalmology outpatient appointment for some time in April. No appointment has been booked for May as that's the first available but can't confirm that appointment as it won't be set in stone till 4 weeks prior to the date when the letter is posted out to me. I need that appointment in April so Miss 14 doesn't miss 1 1/2 weeks off school for 1 appointment in Brisbane. But can I move it forward, YES if I can be in Brisbane by 17th March or NO it's that appointment in May or wait till September. How if they can't set the appointments in stone till 4 weeks before said date can I not get an appointment in April, they should only just be starting to book those in now. (6/3)

"My baby boy needs to go back and see his physio and baby doctor from RBH, he has now gone from top of the list to bottom of waiting list since changeover, he is behind in Milestones and this is concerning I was told I just have to wait"

"My son had an anaphylactic reaction to something we didn't know his was allergic to a couple of weeks ago. We were referred to Lady Cilento hospital for allergy testing. Two weeks later I received a letter saying that they had received the referral. Two days ago, nearly a month after the reaction that had my son in Nambour hospital and sick for nearly a week, they finally called me to offer me the next available appointment. It's 29th February 2016."

RE outdoor gardens and sun exposure - "Yep they expect us to fill in time when waiting for a shuttle bus by using them areas. As I told them those areas are not suited for my son, most parts of the day due to not enough shade which means overheating which can bring on a seizure".

"Before the switch, there were three children's cardio thoracic surgeons and now there is one."

A Mother was told on Wednesday that her child that was needing to be admitted to PICU as she is High Dependency was not able to be admitted as there were not enough beds in ICU, they then told the parent an ambulance would be transferring them from LCCH to the Gold Coast Hospital. The mother then organised for hubby to fly home from rural township where he worked to come and take care of the other daughter, by the time he arrived the transfer was cancelled and a bed was made available in PICU, on this day there were 9 other parents awaiting beds and were not able to be admitted at that time.

"In August my son had surgery to remove cancer from his lungs, I was told there would be a follow up appt for November, just prior to the transition of LCCH. I received short notice of a cancellation and was told I would be given an appointment asap. Since there has been issues with RCH sending mail to wrong address I have not been getting my mail from the new LCCH, despite following this up with admin staff on many occasions. When I followed up about my appointment that was cancelled in November I was told in January I should have an appointment, I soon received a text informing me that I had an appointment the next day, this was impossible for me to attend as we live 2hrs away and would require my wife to take time off work.

They then told me it would be rescheduled asap. It was only because I had been in touch with my specialist that I was able to obtain an appointment in Feb. Even after again contacting admin and confirming postal address they still were sending mail to the wrong address and had the wrong address listed. In February at the appointment we were given the tragic news that our son's cancer had progressed and was aggressive and is now under palliative care plan, this news came at a shock and unexpected, if we had attended our appointment in November we would have had a different outcome as we would have had more time to prepare and spend with our son"

"We would like to finally get there for an appointment without them cancelling them on us - to date they have cancelled 27 on us without our knowledge & for them to actually read the child's records instead of booking them straight in for double hip relocation without consultations or x-rays & ultrasounds"

"Oh not to mention the cancellation of surgeries due to shortage of theatre staff. And further delay of ops because no picu beds available post op."

Standard letter received by many -" our records indicate (your child) has an appointment booked to see (DR etc), You will be advised in writing of your next appointment 4 weeks prior to the appointment date.

We wish to advise that the active period of your child's doctors referral has expired and therefore this referral is no longer valid. You will need to discuss this situation with your child's doctor. If

your child's doctor believes that your child does require continuing care from this clinic, another referral requesting ongoing care is required. "

**\*info about charges if no medicare card \***

"Please note that a continuation referral is required for any further appointments at this clinic" - the concern with this is firstly many have found they actually didn't require a referral, others have found that their name was on a waiting list but no patient file was on record, for rural and regional and remote families the referring doctor can be a lengthy trip and Patient Travel Subsidy Scheme funding for the travel expenses or for travel to be provided"

The other issue is that many parents are finding out their prescriptions are expired and are unable to obtain their medication and often this script is only available via LCCH, most have found out that the script had not expired it was that there was no record of the script on their file as a result of transfer of records, much the same as the "expired referrals"

This is a very small example of the parents complaints and they are not isolated incidences, and these are complaints that have come directly to me just this week. Previous complaints have been similar and other circumstances in regards to pain medication not been administered for 6-9hrs while child in excruciating pain as a result of staying at hospital in first few days, the delay was due to no one knowing where the medication was.

#### RURAL PATIENT CONCERNS -

As no extra accommodation was provided to coincide with the opening of the hospital and most subsidised accommodation is avail in Herston a shuttle bus was promised by QCH to assist families and patients to travel to the new LCCH. This bus was then not arranged and funding applications lodged by Childhood Cancer support and Ronald McDonald house and Leonard lodge for a shuttle service was refused. It was not until a petition and media attention that a bus was put in place only days before the opening. This bus allows parents to travel only to LCCH (a one way service) at 6am, 7am and 8am and then provides a service from LCCH to Herston at only 3:30pm, 6pm, 7pm and 8pm

This schedule is not sufficient and is often over crowded as parents rely on this service for a direct route to a hospital in a city they are not familiar with. There is public transport however most services are a bit of a walk from the accommodation centres and many are limited in access due to the sick children they are caring for.

Other issues are that families who are staying on ward with their child can not freely jump on a shuttle bus and quickly travel home to gather supplies etc. The fact that a hospital shuttle bus only allows patients and families to travel to the hospital before business hours and return only after school or dinner makes life very hard for people who do not have other supports close by or are nervous or anxious about using a public system (many do not even have buses in their home towns). A direct shuttle service offering round trips and regular return services would allow parents some flexibility in their day and a much quicker travel time.

Initially CHQ had promised those who were immunosuppressed would be provided taxi or parking vouchers as it was a risk to the child's health travelling on crowded buses, however this was quickly changed when parents were asking for vouchers and were then told they would need to be in financial hardship.

Until recently the bus was not equipped with a wheelchair facility creating further difficulties for families who had no choice but to stay in Herston, even then acquiring taxi vouchers as promised was a huge task



and often parents were denied vouchers and told they should use public transport, despite the health risks for some of these children. Clearly discriminating against those who were wheelchair needy. The bus now has a wheelchair facility for one wheelchair and this is now creating issues as there are often more than 3 patients in wheelchairs staying at accommodation but can only access the service at 6,7,8 am. If the schedule was changed to regular round trips this would reduce the amount of people at one time needing the shuttle service and eliminate people missing the bus as the wheelchair facility is already been used on those trips.

if there was a bus scheduled for every hour or every second hour on a loop run this would allow the rural families to have better access to the hospital and family visits when the hospital is an inpatient with much less restriction.

Other concerns have been parents flying down for appointments and as results were not available or accessible or their child's file was not on record they have been sent home with out any medical consultation. Often parents have taken days off whether it be to care for other siblings or to take the child to Brisbane for the appointment, for children who are physically unwell or limited this can also be a very tiring day of travel for absolutely no reason.