



## Friends of Brain Injured Children ACT (Inc) Spring 2012

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**Mandy Hudson – Office Administrator**

**A member of SHOUT Inc  
(Self Help Organisations  
United Together)**

### PRESIDENT'S REPORT

Well here we are in a shiny new year for the Management Committee, with some shiny new members and new office-holders. My name is Ngaire Kinnear, and I am honoured to have been elected President for the 2012-2013 committee year. I've been serving as a member on the committee for about six years now so I hope I've picked up some of the tricks! I have a couple of items on the agenda for the coming committee year, and I hope to leave a good contribution to the history and development of FBIC.

The AGM was held on Monday 10th September, electing some new committee members, saying fond goodbyes to some retiring long-servers, and shuffling the remainder about a little.

Rory Mulligan and Sanders King have moved on to other things for now, after serving the committee for some years and with some fantastic contributions - Rory says he may well be back in the future (though he may only have said it to stop us clinging to his legs). Thank you both so much for your contributions over the last few years.

Our policy of electing two parents has paid off really well, and this year we even have three. Jim Sharrock, now in his second year and doing an amazing job, including organising the upcoming Walkathon event, takes on the 'mentor' parent role, and we welcome Fiona

West as the new parent member for this year. And then we have the great good fortune that Ron Cruikshank, last year's 'mentor' parent, is keen to keep his hand in.

We are also joined by Gabi Monus, whom most of our families will know well, a new member by the name of Peter Leek, a former paralympian, and our new Treasurer Terry Watson has been kind enough to take Rory's place with us this year. In accordance with our constitution, Libby has stood down as President for this year having served three consecutive years, and the committee has elected Yours Truly to the position. Libby remains of course closely involved with all activities in her new position as Vice President.

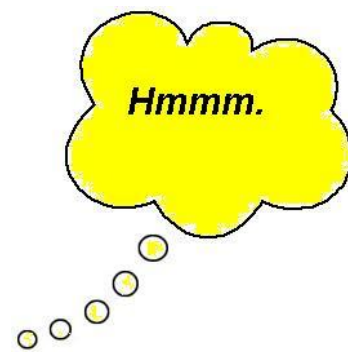
I have to acknowledge the great work of the committee last year in a number of successes, but before I do I want to acknowledge the amazing work of our staffer, Mandy Hudson, in driving things, keeping things together, placing the right

kick on the right patookas at the right time, and generally making things work. Mandy, you're incredible and we are very lucky to have you on board. To the 2011-2012 committee: Rory Mulligan really gave us drive and focus on some new strategies for fund-raising, in applying for philanthropic grants of varying kinds, from which we had some fantastic results including grants from the St George Foundation, the ANZ Foundation and the Commonwealth Bank. The Snow Foundation continued their invaluable support, Disability ACT continues to provide a grant for our administrative work. Then late in the year, the Citizenship Committee of KPMG succumbed to Libby's charm and verve, and decided to donate their annual fundraiser to us! See the report in this newsletter. Other activities were Libby's Open Garden event, two Bunnings sausage sizzles, the very valuable visits from Dr Ian Hunter and Mengde Yu, the Sunset Cruise back in October, as well as a number of bits and pieces in the background.

What a year - there was a lot of stuff going on, and fantastic success rate for effort. Quite an act to follow, but I do think that last year's successes have given us some new and really solid blocks in our foundations that we can build on this year. And with the energetic new committee I saw assembled at the AGM, I think it's going to be another good one.

I'm really looking forward to working with all of you, committee, families, members, and anyone interested, for the coming year.

**Ngairé Kinnear**  
**President**



#### **THOUGHTS FROM LIBBY**

This year I have stepped down after three years as president, as our constitution requires. We are very lucky to have Ngairé Kinnear take on the presidency, bringing lots of experience and enthusiasm. I plan to be involved in other ways, including staying on the committee. I will be just as available to help you all.

We have come a long way since I first became a member of the committee eight years ago. In those days there were just thirteen families and we were far from flush with money. We now have thirty families and are able to offer much more financial help for therapy. Even better, Friends of Brain Injured Children has increased its ability to give further value to our families. Helping to fund therapy is still our main purpose, but we have added several projects for the benefit of families.

Our families can meet together at the children's parties for support and talk, we have a useful website, the Snow Foundation has funded Mandy to undertake more family support and information, we are getting good at raising money and we have developed a really strong network among other helpful agencies.

Our grant from Westpac is used to bring two therapists from Melbourne for consultations with a number of children. Both Mengde Yu and Ian Hunter are leaders in their fields, and parents seized the chance to consult with

them without having the effort and expense of a visit to Melbourne. The visits were so successful we will ask Mr Yu and Mr Hunter to provide follow-up visits.

Committee members have been attending meetings about the National Disability Insurance Scheme. At this stage we are not sure how helpful the Scheme will be in providing early intervention to children with brain injury. One of its principles is to reduce disability through early intervention, but there is some uncertainty about what therapies will be regarded as acceptable. In our organisation's experience, many non-intensive mainstream therapies are not particularly effective.

We will be pushing for the acceptance of therapies such as Conductive Education, Bowen Therapy, acupuncture, massage, and osteopathy, when offered by practitioners with proven expertise with children with brain injury. Even if these therapies are eventually included in the NDIS the funding is unlikely to meet the full needs of our children. I certainly see a need for our services well into the future.

Our small organisation is able to punch above its weight by using networking to keep in touch with the disability sector and seek children we may be able to help. To this end we have participated in the Community Living Program's Expo, the Disability Service Providers Network, National

Disability Insurance Scheme meetings, Raising the Standard workshops, and the Hands Across Canberra annual lunch. As our membership of SHOUT is important to us I sit on the SHOUT board. Opportunities to speak to other groups have included playgroups for children with disabilities, Zonta and Lions Clubs, and the disability committee of ACT Council of P&Cs. FBIC is represented on two new networks, one of ACT organisations concerned with brain injury and the other of parent groups seeking to improve standards of disability services.

We owe much to the Snow Foundation. Each year they provide generous sponsorship to our families, giving us a solid basis of therapy funding. I know each family is immensely grateful for the Foundation's support.

The Southern Cross Club is also consistent in its support. Not only do they offer us a grant each year, they offer the MS Southern Cross at no cost for our fundraising dinner cruise.

We are also looking at ways to help families add to their own funding. The Walkathon on 17 November is the first step in this direction. It is getting close, so please watch out for emails from Jim Sharrock to make the most of participation. It is going to be great year for our children.

**Libby Steeper**

## THERAPIST'S ARTICLES

### Point Percussion Therapist Visit - Mr Mengde Yu

Point Percussion Therapy (PPT) is a breakthrough technique developed in the 1980's by a Chinese orthopaedic surgeon, Professor Wang Zhaopu. PPT is a physical exercise program. Although it is not a complete answer to cerebral palsy, with early intervention it provides a useful practical tool that has positive results. Mr Mengde Yu, a leading therapist has modified PPT technique into a simple format to suit a family program. The simplified PPT exercises are simple, safe and easy to use at home; they are just like a baby gym and baby aerobic exercises for your special child.

Seven children were given the opportunity to be seen by Mr Mengde Yu in February when he once again paid a visit to Canberra. My daughter Caitlin was one of them.

We have been seeing Mr Yu for the past seven and a half years. Our first visit was when Caitlin was just four and a half. Jane and I had been spending a couple of hours every night at the swimming pool trying to get Caitlin to walk for about a year. Initially we started with the water up to her armpits then slowly progressing to her ankles. Despite all of this work she refused to walk on dry land without holding onto one hand.

Pat Jenkins asked us to see Mr Yu when he held one of his clinics at the Cerebral Palsy Alliance facility in Allambie Heights in Sydney. We took the drive and were waiting in the waiting area when he called us to come into his office. He watched us walking with Caitlin down the corridor and into his office. As we sat down he said "there is nothing wrong with your daughter she will walk she just needs to strengthen the right muscles". Jane and I were shocked he could say this without even having checked her out. What happened next blew us away, he proceeded to tell us how she sat, how she carried herself, all of her nuances; he nailed it to a tee. This gave us a lot of confidence in what he said as we entered his office. He allowed us to video his

exercise regimen and he told us if we stuck to it she would walk.

We drove back to Canberra and tried like crazy to do the routines with little or no success. Caitlin would not cooperate she did not want mummy or daddy to be a therapist she wanted them to be a shoulder to cry on. Jane found a paediatric physiotherapist who looked at Mr Yu's program and was also able to inspire and motivate Caitlin into doing the exercises. Six weeks later with five sessions a week provided by the Snow Foundation our daughter took her first independent steps.

Since those early days Mr Yu has been an integral part of Caitlin's therapy as he continues to work on her gait, fine and gross motor skills. We have her assessed each year for an independent view following her treatment in Hong Kong and we use his exercise regimens when she is back home in Australia to maintain the progress we get from the treatment in Hong Kong.

I thoroughly recommend an assessment by Mr Mengde Yu; he has an enormous capacity for not only diagnosing the problems with our children he also is able to give solutions to removing the barriers that have stopped them from being able to achieve greater independence.

Further reading:

**Sean McCandless**

<http://members.optusnet.com.au/mengyu/>

## Dr Ian Hunter visit By Fiona West

We met Ian Hunter back in April. We are very new members of FBIC and especially keen to take advantage of every opportunity to assist our son. Felix is five years old and has mild left hemiplegia. He was born at 29.4 weeks but his prematurity was not the cause of his physical disability. Felix has a very rare genetic liver condition. The condition was not diagnosed until after he suffered a brain bleed at 5 months caused by the liver condition. He will need a transplant one day but for now he is stable and our efforts are concentrated on his physical rehabilitation.

How lucky we were to meet Ian so early in our journey. He took a very comprehensive medical history and has an entirely holistic view. This is so reassuring when your child has complex issues. Mostly though, Ian has helped by suggesting a more methodical approach to our son's therapy. Like all parents in our situation, we try to incorporate therapy throughout the day. We've tried to do bits here and there and more demanding workouts when we can find the time. But Ian has shown us a better way. He designs a program exactly suited to our child's needs and specifies the exact amount of time to be spent on each exercise. In our case, we do a thirty minute sequence twice a day with individual

exercises lasting between one and five minutes. This is manageable for us as we can fit in a sequence before preschool and another in the afternoon. Once we made a commitment to the program, it simply became a part of our daily routine (with one day off a week). While the sequences can be hard work for all involved, it can also relieve some of our stress simply to trust that you're in the hands of an expert. Indeed, we're already seeing very positive results after only a few months.

One of Felix's exercises is to hang from an overhead bar. When he started, he could not do this for more than a second. He has since mastered a playground flying fox on his own! Of course it was the systematic approach of doing this twice a day that made the difference. What a joy it is to see the strength increasing in his left hand and arm. Likewise, Felix can now 'tummy crawl' at a great rate. These two exercises are the hardest for Felix to master and in the early days he would protest vociferously at having to do them. But we persevered and they are now two of his favourite exercises. Stepping over hurdles and climbing ladders can also be a lot of fun. Ian by the way always has plenty of advice when it comes to sourcing equipment. He tweaks the sequence via skype conferences every couple of months and we look forward to both short and long-term benefits of the program.

Fiona West

### HAPPINESS... by Libby

Happiness is an inside job, I've been told. Looking around our lovely FBIC families I've noticed that managing life with a child with a disability does not prevent happiness. Our families are busy, stressed, very short of time, but still cheerful.

Nonetheless, most people wouldn't mind being a bit happier, so here are some hints about happiness for families under pressure. I have adapted them from Sophie Scott's book, Road-testing Happiness.

**Count your blessings.** Remember things you are grateful for. Hug your children and kiss your partner every day.



#### **Nurture your relationships.**

Happiness is contagious. Invest time and energy in the people who bring joy into your life.

**Use your strengths** to find your passion. Find something you love doing to increase the fulfilment in your life.

**Avoid overthinking** and comparing yourself to others around you.

**Don't be afraid to volunteer.** The happiest people in the world are also the most giving (but not at the expense of your family, of course).

#### **Eat well to feel well.**

Nurture your mind and body with good food and exercise.

#### **Make happiness a priority.**

Don't put it off to a distant future when you have no problems. That time may never come and you will miss a happy present





## Technical Aid to the Disabled ACT (TADACT)

assists people of any age with any type of disability by designing and making innovative equipment which is otherwise unavailable. TADACT can also modify commercially available equipment to make it better suit the client's needs, repair equipment, or provide specialized advice. The equipment is made or modified by skilled volunteers who donate their time to providing innovative solutions to problems. They can also provide advice if they are unable to help or can refer you to other services.

TADACT aims to help people of all ages with any kind of disability to live more independently and to have increased quality of life. One avenue that we achieve this through is our Freedom Wheels program (pictured above). Freedom Wheels gives children with disabilities the chance to experience something most of us take for granted – the joy of riding a bicycle. Freedom Wheels is a Modified Bike Service that customises standard pushbikes to give a new kind of independence to children with disabilities and allows them to engage with other children.

Some types of equipment that TADACT are able to make for you and your family.



### Adjustable Height Table and Chairs



### Stimulative Toys



### Stabiliser Wheels

They also make drink holders and a Slope Board iPad Holder combination but do not at present have any images of these. For more information on TADACT and how they can assist you with your equipment needs please call.

TADACT is committed to providing a minimal cost 'design and make' service. The volunteer's labour, ingenuity and creativity are provided free. The charge for the service is based on the cost of materials, the volunteer's incidental expenses including travel to the client's home or workplace, and a small administrative fee.

If you know someone with a disability that has a need, then contact TADACT to see if they can provide a solution. TADACT also welcomes enquiries from people interested in becoming a volunteer. Phone (02) 6287 4290 or email [tadact@tadaust.org.au](mailto:tadact@tadaust.org.au)

*Technical Aid to the Disabled (ACT) Inc*

Phone: 02 6287 4290

Fax: 02 6287 4288

E: [tadact@tadaust.org.au](mailto:tadact@tadaust.org.au)

Address: 27 Mulley Street, Holder, ACT 2611

## WHAT'S HAPPENING



### **KPMG TRIVIA NIGHT – 31ST AUGUST 2012 – CANBERRA SOUTHERN CROSS CLUB WODEN**

On Friday night, just after office hours, a handful of our FBIC members, veterans and clients gathered to attend KPMG's annual charity fundraiser, the Trivia Night.

Libby, our simply amazing committee President, had managed to get herself in the right place at the right time (in that way she has – this time the annual Hands Across Canberra lunch), and crack out the Good Oil (ditto) for some very generous and civic-minded representatives of KPMG's Citizenship Committee, who promptly resolved to donate the proceeds of this financial year's fundraising to our humble cause. Just like that!

On the way into the club I got the feeling it was going to be a largeish event, as the queues were long at the KPMG sign-in sheet – I was not mistaken. I also noted that many were stopping in at the ATM queue on the

way to the function room – a sign that generosity was afoot – and I wasn't mistaken there either. The happy swarm led to a room which was huge, lovely, full of people, and beautifully laid out with a huge Silent Auction and other fundraising activities, and a busy bar in the corner – it was Friday night after all! The FBIC banner had just been put up as I arrived, so we found ourselves a table, bought a round of drinks and settled in. The wonderful hostesses Leah Clarke and Katherine Meagher kicked off proceedings with some warm welcomes, some skilful crowd training, the Rules of Engagement for the quiz, and some explanations about the various other fundraising activities of the night. Then after a few words of introduction to FBIC and thanks from Libby and Melissa (one of our fabulous Mums), the evening began in earnest.

The whole quiz was a lot of fun, and mercifully not too hard. You'll be pleased to know that your representatives acquitted themselves pretty well, and ended up mid-table (that is, the scoring table, not the actual furniture – we were really only on soft drinks most of the time), despite the fact that we were relatively small in number compared to other tables, and had no boys or boy-like people to answer all the sport and action-movie questions.

One great moment was a concerned uncle coming to our table during one of the pauses in between rounds, and discussing his nephew, born earlier this year with a tough birth and resulting CP – hopefully by the time you're reading this we'll have a new family on the books.

The quiz was also punctuated with auctions of very valuable items donated by local businesses and clubs, and here the donors and the hard work of the KPMG Citizenship Committee must get a mention. The range of donors, and the generosity of items donated for auction was just incredible – everything from day spa vouchers, holiday home stays,

kitchenware, a carparking space at Brindabella Business Park, collectors' wine, gym memberships, catering and many more. The number of donors to be acknowledged was just enormous. It all represented tremendous generosity from the donors, and a whole lot of hard work, charm and ingenuity from the members of KPMG's Citizenship Committee. I hardly know where to start saying 'thank you', knowing that all of that was done, in the end, for the benefit of our kids.

Anyway, the story doesn't end there – Leah explained that KPMG's Citizenship Committee has basically committed themselves to helping us out one way or another for the financial year. I don't know about you guys, but I'm seeing sausage-sizzle volunteers...

Some furious receipt-writing was to be done at the end of the night, and then, feeling slightly bewildered at the honour, the good will and generosity from KPMG's community, we chipped the ice off our car windows and smiled all the way home.



**Ngairé Kinnear**

## FBIC'S WALKATHON

Join us for our  
"RIVERWALK"  
On Saturday 17<sup>th</sup>  
November

**FBIC'S FIRST EVER WALKATHON.** An exciting opportunity for FBIC families to raise money for their children's ongoing therapies.

Thanks to the support of our sister organisation 'The Developing Foundation' [developingfoundation.org.au](http://developingfoundation.org.au) in Queensland, FBIC are able to hold a walkathon this year to raise funds for their members. The Developing Foundation have held an annual Riverwalk (sponsored 5 km walk along the Brisbane River) for 28 years.

In 2010 they expanded their Riverwalk concept to Brisbane, Cairns (Far North Qld) and Ballina (NSW). This year the **Riverwalk** will take place in Canberra (admittedly around a lake and not a River) for the first time. Read on:

**WHAT:** Riverwalk (FBIC walkathon)

**WHEN:** Saturday 17th November between 10am and 1pm

**WHERE:** The walk starts at Regatta Point and makes a 5km loop towards Aspen Island and back. The registration table, BBQ and entertainment will be situated near the BBQ area at Regatta point (Commonwealth Park, near Captain Cook fountain)

**HOW DOES IT WORK:** FBIC members receive a donation receipt book for the walk. They then seek sponsorship for their walk from friends, family, work colleagues and the general public. For example, a neighbour may sponsor you for \$10 if you complete the walk. You can collect their money at anytime and present them with a receipt. Their donation will be tax deductible.

**ALL DONATIONS THAT YOU COLLECT GO DIRECTLY TOWARDS YOUR CHOSEN THERAPY.**

The money will not be administered through the FBIC office. The more money that you raise the more you have for therapy.

**CAN ANYONE PARTICIPATE:** YES. Anyone one can walk, roll or ride in the Riverwalk. There will be a \$10 registration fee for non-members. Registration will take place on the day at Regatta point. The registration money will go towards walkathon costs and towards therapy costs of FBIC members.

**FOR MORE INFORMATION:** call Jim Sharrock on 0409660745 or via email: [jimsharrock@internode.on.net](mailto:jimsharrock@internode.on.net)

We also looking for volunteers to help plan the event and to help on the day. Register your interest with Mandy in the Shout office.

**Jim Sharrock**



## VALE. PAT JENKINS

We at Friends of Brain Injured Children were saddened at the recent death of Pat Jenkins. She founded our organisation and, with her husband Dick, was its mainstay for almost twenty years.

Our sympathy goes out to Dick and to her family. In her eighties she passed the reins to a new committee.

Pat became our first Life Member and kept a close interest in the children and families of Friends of Brain Injured Children. I doubt if anyone can surpass her depth of knowledge about brain injury and therapy, or her kindness.

In lieu of flowers at her funeral she requested donations be made to Friends of Brain Injured Children. We are very touched that she had us in her heart. She will be greatly missed by all the families who knew her and were helped by her.

Friends of Brain Injured Children is an impressive legacy of this lovely lady.



## CONDUCTIVE EDUCATION

**Gabi Monus**, is our ACT expert in Conductive Education, and is now a committee member of FBIC. If you want Conductive Education please contact Gabi.

Gabi also plans a Mums and Children's group at Cranleigh. This is a fabulous opportunity.

Contact details are Gabi on 0415 347306 for more information.

## DISABILITY INFORMATION SUPPORT HUB



This exciting new venture is a co-location of services for people with disability that includes Belconnen Community Services, Woden Community Services, House with No Steps and Disability ACT. The DISH brings together shared expertise, skills and knowledge and a consolidation of resources into one accessible space in Belconnen.

**Call:** The DISH@oatley on **(02) 6205 9331** or Disability Information Service **(02) 6207 1086**  
**Email:** [disabilityact@act.gov.au](mailto:disabilityact@act.gov.au)

**Website:** [www.dhcs.act.gov.au/disabilityact](http://www.dhcs.act.gov.au/disabilityact)

**Visit:** The DISH team at 60-62 Oatley Court Belconnen

## Black Mountain School Northcott Disability Service

Northcott Disability Service will deliver an after school and vacation program starting first term 2012 for teenagers with high needs including those with autism. This program will be based at Black Mountain School. Ten places will be available at each program per day.

Contact: Taryn Bankier, Area Manager, Northcott Disability Services  
Ph: 6297 6899  
Email: [taryn.bankier@northcott.com.au](mailto:taryn.bankier@northcott.com.au)

## Belconnen Community Centre Belconnen Community Service

Belconnen Community Service will deliver an after school and vacation care program for teenagers with high needs including those with autism starting first term 2012. This program will be run from the Belconnen Community Centre. Ten places will be available at each program per day.

Contact: Sonya Roelofse, Ph: 6264 0252  
Email: [sonya.roelofse@bcsact.com.au](mailto:sonya.roelofse@bcsact.com.au)

## Cranleigh School

Belconnen Community Service will also deliver an integrated vacation care program for ten weeks each for children with high needs. Ten places will be available later in 2012 for children with disability and ten places will be available for children without disability.

Contact: Lee Pederick, Ph: 6278 8106  
Email: [lee.pederick@bcsact.com.au](mailto:lee.pederick@bcsact.com.au)

## Malkara School Communities@work

Communities@work will deliver an integrated vacation care program for ten weeks for children with high needs. Ten places will be available later in 2012 for children with disability and ten places will be available for children without disability.

Contact: Lee Maiden, Executive Director, Children's Services, Ph: 6293 6514

## ...ABOUT BETTER START...

Better Start provides funding for early intervention services. To access Better Start children with an eligible diagnosis must register before they turn 6 years old. Families will have until the child turns 7 to access the funding.

Children are eligible for Better Start if diagnosed with one of the following disabilities:

Cerebral palsy  
Deafblindness  
Down Syndrome including mosaic Down syndrome  
Fragile X syndrome with full mutation  
Hearing impairment  
Vision impairment

To contact and register for Better Start call the Carers Association in your state or territory on 1800 242 636

For more information go to [www.betterstart.net.au](http://www.betterstart.net.au)

Other sources of assistance and support are:  
Carer Allowance and Carer Payment  
[www.centrelink.gov.au](http://www.centrelink.gov.au)  
Medicare  
[www.medicare.gov.au](http://www.medicare.gov.au)

My Time Peer Support Groups  
[www.mytime.net.au](http://www.mytime.net.au)

Raising Children network website  
[www.raisingchildren.net.au](http://www.raisingchildren.net.au)

State and Territory Disability Services.





**FBIC IS PROUDLY SUPPORTED BY THE FOLLOWING:**

**HOLIDAYS HOMES FOR FAMILIES**

Ronald McDonald House—please check out the website for more details—  
[www.rmch.org.au](http://www.rmch.org.au)

OR  
Starlight Foundation—follow the links  
[www.starlight.org.au](http://www.starlight.org.au)

**Remember, for all your equipment needs, including nappies, please call ACT Equipment Service 6205 2599**

**OUR COMMITTEE 2012/2013**

**PRESIDENT:**  
Ngaire Kinnear  
**VICE-PRESIDENT:**  
Libby Steeper  
**TREASURER:**  
Terry Watson  
**SECRETARY:**  
Ron Cruikshank

**COMMITTEE:**  
Jim Sharrock  
Fiona West  
Gabi Monus  
Peter Leck

**PUBLIC OFFICER:**  
Libby Steeper

**STAFF:**Mandy Hudson

**WEBSITE INFORMATION**

Our website is becoming a source of information for all our members and associated organizations.

If you have any information regarding your child’s therapies, public notices, or just a blog, the website is a great way to get information out there.

If you have any queries about the website, please give Mandy a call in the office: 6290 1984.

[www.fbic.org.au](http://www.fbic.org.au)

**NDIS INFORMATION**

More information will be on our website and there is a pilot program in the ACT, please go to our website for further information provided by Sean McCandless. You can also contact Mandy in the office for further information.



**ANZ BANK**

**COMMONWEALTH BANK**