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The MS Waikato Trust supports people affected with Multiple Sclerosis and allied neurological conditions; the MS Waikato Trust is affiliated with the MS Society of New Zealand. If you would like further information on our services, please contact us:

**Life Unlimited Building
20 Palmerston Street
PO Box 146, Hamilton 3240**

**Ph: 07 834 4740
mswaikato@mswaikato.org.nz**

**Liz - 07 834 4741
Tracey - 07 834 4745
Janet - 07 834 4740**

ManuScript is brought to you by:



Sir John Logan Campbell
Residuary Estate

'Grand Master' - Trump That!



Mike Barton

Me - I love card games. I've whiled away many an hour on sports trips, school camps, long summer nights at the beach, grotty days during the school holidays - even rushed hands during tea and lunch breaks at work. I reckon I'm a pretty dab hand at most forms of cards and can hold my own in any company and enjoy the art of bluffing, feinting, deciphering a hand and at times down right cheating. And then there's Bridge - a game I had never played and one that had always intrigued me. So, when I noticed an ad in the paper offering a six week beginners course at a local Bridge club I went along fully expecting the resident members to recognise my obvious potential, fall in love with my witty repartee and roll about laughing at my table antics.

Rule 1 - no talking to your partner; no eye contact with your partner; no touching any part of your face or body, no winking, smiling, coughing, twitching, involuntary spasms - breathing is optional. In short - make a call (or pass) and shut up until the hand is complete. One thing about Bridge - it is glaringly obvious when you do something wrong. I was partnered with an old dear who most people would happily accept as their grandmother and would gladly walk through the spooky forest to visit - wolf or no wolf. But when I enthusiastically trumped

her first lead (showing her what a great partner I was going to be) I was met with this withering stare, there was an audible gasp from our opponents and at every other table play stopped as they all turned and stared at me. Oops - I bet we'll have a good laugh about that at supper time I thought - not! To cut a long and painful story short - at the end of six weeks I was not much more wiser about the subtleties of the game. It appears I didn't endear myself to the members - apparently yelling 'take that sucker' when I won a trick and fist pumping the air was not considered good form. In the end I filed that one under experience and went back to 'Fish' and 'Old Maid' with my mum's buddies at the local church hall.

That's a long winded way of saying It takes a person with certain qualities (self-control for one) to make a good Bridge player. Mike Barton - part time gym bunny - is one such person.

Mike has been playing Bridge for 30 years so he knows a bit about the game. He tells me in a hushed voice that being good at Bridge is "10% brilliance and 90% not doing anything stupid". Mike is a serious player and in addition to attending club nights twice a week he participates in the numerous tournaments on offer. The aim at these tournaments is to finish in the top third of the field. If you achieve this you are awarded points ranging from 10 if you win down to 1. When you accumulate 500 competition points you can call yourself a 'Grand Master' - Mike achieved that lofty status in December. And no he doesn't get a fancy hat, a flashy badge or T-shirt to show he is one of them but he does get the swagger - you know it - back off dude I am a 'Grand Master' - grovel at my feet!

Mike recently competed at the nationals (Congress) held in Hamilton

ms.

which attracted 350 people and was played over 8 days with three sessions a day. In all each competitor plays 60-65 hands a day with a partner or as a team of four. Over a day's play all competitors get to play the same pre-set hands so there is no luck involved. Each pair is judged on how well they played an individual hand compared to everyone else. At Congress Mike and his partner weren't quite on top of their game but they did well enough to make the top third.

I asked Mike what I thought was a relatively straight forward question and immediately regretted it. "What is the best hand you have played Mike?" It was like asking Brian Mahood what his most successful operation was! Let's put it simply. There are 13 cards in a hand. You must win 7 tricks to score 1. The lowest call you can make is 1 and the highest 7 (by winning all 13 tricks).

Mike represented Waikato/Bay of Plenty at the Inter-provincials in Auckland in November. Mike won selection for the 4 person team after competing in trials. He also represented Canterbury in 2005.

And to finish with let's confirm Mike's credentials to appear in these hallowed pages. Mike was diagnosed with relapsing/remitting MS in 2006. At the time he was in Christchurch and had his own 'Mr Mint' type business (engraving, cutting keys) in Rangiora. MS played havoc with the engraving side of things so Mike shut up shop and moved to Hamilton to be close to family (he's a Te Awamutu lad). He has been on Avonex since early 2007 and the drug has been having the desired effect allowing him to work until he was recently made redundant at the Waikato Times.

Ian Maxwell

ME / CFS Update

The ME/CFS/FM Christmas lunch in December was a successful event and enjoyed by many. Over 30 people enjoyed catching up over a lovely meal. Santa gifts were also shared and spot prizes given out. Matthew King and his young music students entertained us and provided lovely background music playing Christmas carols and beautiful folk songs. It was more special this year because we also farewelled Helen. Many of you took this opportunity to share your appreciation to Helen for the wonderful service and support she has offered over the years. Frankie made a lovely speech and presented

Helen with flowers from the Board of MS Waikato Trust. She will be greatly missed and we wish her well in her retirement.

ME Christmas Lunch



Linda and Monica



Lee, Julia and Helen



Andrea and Maree

Relationships

The November Education Group meeting was a facilitated group discussion on the topic of relationships. Discussion focused mainly on managing and maintaining relationships with family when chronically ill especially intimacy and closeness with a spouse/partner. The overriding ideas shared were to treat people kindly and with respect.

To rub 'dis' off disability and focus on 'ability' was a great idea and a great attitude for both the well and unwell family member to adopt - this encourages the person to be seen as someone experiencing an illness and not being defined by it.

Having a sense of humour helps to ease tension. Doing low energy activities that you both enjoy can help to maintain a close connection such as playing cards or board games, playing music, looking at photos, enjoying watching a sunset (or rise) together, lighting a candle at dinner time, going to a daytime movie, leaving little

notes of love and appreciation for your partner to find - write a love note on the bathroom mirror with a lipstick!

If fatigue is hindering your ability to watch your children play sport and other activities ask someone to take a video of the game and then watch it with them. This way you won't miss out on their achievements.

The topic then turned to 'communication'. Ideas shared were to remember to praise and be appreciative of the support being offered. Keep talking (or write if you have difficulty verbalising your feelings) - it helps to stay connected. When confronted with an emotional reaction, see the reaction for what it is and try not to be drawn into the emotionality of the moment - remember that anger is a secondary emotion, often following feelings of frustration or guilt. Knowing this can help to see the other side of the issue from their perspective.

Tracey Larsen

The Christmas Dinner

There was a good turnout for our Christmas dinner at the Hamilton Workingmens Club, where we enjoyed a buffet dinner. Adam Muir presented Trustees with a cheque of the funds he raised with the Kawhia Cruise, overall this raised \$4,315 and members met Joanne and Ray Young who assisted Adam with the event. Graham (BOT Chairperson) took the opportunity to sum up some of the highlights of the year – the donation from the Sutherland Self Help Trust to allow us to purchase two new cars, the Kawhia Cruise and our education sessions. He thanked our volunteers and staff and farewell Helen. Overall, we had good food, good company and a very pleasant evening!



Adam and Trustees



Adam, Ray and Joanne



Rex and Judy



Pippa and Brian



Maureen and Marion

The 'not so new' girl!

Ten years ago I was the new girl in the office; it was my first day in a new and challenging role for which I was beginning a two week induction. I have to say that this time has gone incredibly quickly!

I have been kept on my toes organising fundraisers and events – 10 golf tournaments, MS Awareness weeks, Christmas dinners and movie nights to name but a few. As a not for profit organisation we don't receive government funding and are dependent on fundraising and the generosity of funders, so making grant applications and preparing the accounts is also an important part of the role.

Being a small organisation (in terms of staff) we learn to be quite versatile, the roles are quite varied and it certainly keeps it interesting. Over this time I have met some wonderful and very inspiring people and seen a number of changes in the organisation. Our client numbers have grown considerably; we also formally brought the ME/CFS group under our umbrella employing an additional staff member. We've celebrated 50 years of service, changed

our branding, redesigned the newsletter, created a new website and relocated the exercise class.

I have been fortunate to work with such dedicated staff as Liz, Tracey and until recently Helen. Liz has also been with the Trust for almost 10 years. Trustees Graham Haines, Caroline Allbon, Mark Etheridge, Frankie Letford and our Admin volunteer Monica Booker have all been working in a voluntary capacity for the Trust for over 10 years. Over the years they have shared their skills and knowledge and given many hours of support for which we are very appreciative.

Janet Buckingham
Admin Manager



Toxin from tobacco smoke could increase pain in spinal cord injury and worsen MS

A neurotoxin called acrolein found in tobacco smoke that is thought to increase pain in people with spinal cord injury has now been shown to accumulate in mice exposed to the equivalent of 12 cigarettes daily over a short time period.

One implication is that if acrolein is exacerbating pain its concentration in the body could be reduced using the drug hydralazine, which has been approved by the U.S. Food and Drug Administration for hypertension, said Riyi Shi (pronounced Ree Shee), a professor in Purdue University's Department of Basic Medical Sciences, College of Veterinary Medicine, and Weldon School of Biomedical Engineering.

The drug has been shown to be effective in reducing acrolein levels in research animals, and Shi is working to develop a low-dose version for that purpose in humans.

Mice were exposed to a level of acrolein equivalent to 12 cigarettes per day over three weeks. Previous research has focused on acrolein accumulation in the respiratory system but not in the bloodstream and spinal cord. It is known that acrolein is accumulated in urine in human smokers after years of smoking.

"This is the first animal study demonstrating that an acute short term of weeks of smoking could also cause acrolein to accumulate in urine and more importantly in spinal cord tissue, a part of central nervous system known to be vulnerable to acrolein, he said.

The researchers documented the concentration of biochemical markers for acrolein in the urine and spinal cord. Findings, appearing this week in the journal *Neuroscience Bulletin*, indicate the accumulation of the

toxin was about 50 percent higher than normal, a level known to have pathological implications.

"The data indicated that acrolein is absorbed into the circulatory system and some enters the nervous system," Shi said. "It is expected that these findings may facilitate further studies to probe the pathological role of acrolein in the nervous system resulting from smoke and other external sources through long and short term, both active and passive exposure."

The research paper was authored by Melissa Tully, a graduate student at Purdue and the Indiana University School of Medicine; Purdue graduate students Lingxing Zheng, Glen Acosta, and Ran Tian; and Shi.

Acrolein is produced within the body after nerve cells are damaged. In spinal cord injury and in multiple sclerosis, the myelin insulation surrounding nerve cells is destroyed and the nerve fibers themselves are damaged by acrolein. The toxin acrolein also is found in air pollutants including tobacco smoke and auto exhaust.

"It is already known that smoking can increase pain for people with spinal cord injury and worsen the condition of multiple sclerosis, but we don't know exactly why," Shi said. "I am saying that acrolein might be the key culprit here and that inhaled acrolein could intensify multiple sclerosis and increase pain sensation."

The research is ongoing and was funded by the Indiana State Department of Health, the National Institutes of Health, and an Indiana CTSI CBR/CTR Pilot Program Grant.

Source: Purdue University © 2014 Purdue University (05/12/14)

MS Research Alliance

By Life Scientist Staff | Posted in Neurological disorders on 18 September, 2014

MS Research Australia has joined the International Progressive MS Alliance, a global alliance formally established in 2013 to work towards ending progressive multiple sclerosis (MS).

Coordinated by the MS International Federation, the alliance includes organisations in the USA, UK, Italy, Denmark, Spain and Canada.

MS Research Australia has pledged \$1.1 million over the next 3 years towards the collaborative project.

MS is a chronic, often disabling disease that affects the central nervous system. Fifty per cent of people with relapsing-remitting MS will develop progressive MS within 10 years, while 90% will develop progressive MS within 25 years.

Treatment options are limited for progressive MS and much less is known about this form of the condition. Around 10% of people are diagnosed with the primary progressive form of MS from the outset. Their neurologic functions steadily worsen and they typically experience only temporary or minor improvements, but for most, there are few remissions.

The alliance will fund projects that look at key challenges in progressive MS research, such as better understanding

progression of the disease and trials to test new therapies, as well as support the formation of international collaborative research networks.

"Working in isolation on an issue such as progressive MS risks duplicating efforts or making only slow progress," said Dr Matthew Miles, CEO of MS Research Australia. "By enabling global collaboration, this alliance is dedicated to fast-tracking the type of discoveries that can truly change lives."

The first round of 22 research grants awarded to investigators in nine countries was recently announced. Australian MS researcher Dr Steven Petratos from Monash University obtained funding to support his research into preventing the degeneration of myelin and nerve fibres in MS, which aims to prevent illness progression and deterioration.

MS Research Australia joins the alliance as a managing member, with a key role in the executive committee and contributing technical advice and expertise. MS Research Australia will also continue to fund research into progressive MS in Australia

- See more at: <http://lifescientist.com.au/content/health-medical/news/ms-research-alliance-1162096269#sthash.MoqatFm6.dpuf>

HD Research

To test or not to test?

This is a question many family members who face Huntington's Disease can sometimes struggle with.

To help with this decision the Huntington's Disease Youth Organisation, HDYO, has a wonderful section with a forum for people to ask questions and discuss experiences about many topics. There are some particularly good conversations about deciding whether to get tested or not. The great thing is you can contribute to the discussion if you chose to, or just read what is there. To see what others are thinking about, their reasons for why they are testing (or not) may be helpful – it's well worth a look!

The web site link is <http://en.hdyo.org/> On the home page click "Young Adults" then "Forum" (directly above Young Adults).

If you have decided that you would like to be tested for the Huntington gene the process begins with a phone call to Auckland Genetic Services on 0800 476 123. You can make this call when you feel ready to do so. Following the initial meeting with the Genetic Service they make a referral for the assessment of psychological and emotional functioning, ability and also to assess the client's level of support they have available to them. Once this assessment has been completed the Genetic Service then advises the client as to the next step in the process, which involves a simple blood test.



HUNTINGTON'S DISEASE YOUTH ORGANIZATION

The client has the option of where the results of the blood test are sent, this may be the Genetic counsellor who they initially visited, their GP, or the psychologist who saw the client for the assessment of psychological / emotional functioning. If the client is not yet ready to hear the results they are placed on file until the client feels ready. The results are never sent directly to the client's home.

After the results have been received a follow up consultation can be made with the psychologist if the client feels the need to discuss any further concerns.

The psychologist for the Waikato DHB area is Ron Dick who is based at Waikato Hospital. He also receives referrals for pre-symptomatic counselling.

Tracey Larsen

The Human Brain Bank

Just before Christmas I received fantastic opportunity through an invitation from Shirley to visit the Centre for Brain Research at the University of Auckland Medical Faculty of Medical Health and Science. Prof. Richard Faull invited Shirley for a tour of the human brain bank and research facility and lunch. We had a great day out hearing about the evolution of the brain bank, Prof. Faull's passion for the research into HD, and the dedicated team he has established to assist in his endeavours. He shared that they now have over 400 donated brains in the bank covering not only HD but also other neurological conditions such as Parkinson, Dementia and Stroke to name a few.

New Zealand is the only research centre in the world that uses human brain tissue for research and understanding the functions of the brain. During the tour of the research facility we were introduced to national and international

PhD students who shared their ideas and research aims. What a hive of activity!! As neurological diseases are among the top five causes of death and long term disability, more research is essential. Supporting brain research through volunteering, financial donations and brain donation were therefore also discussed. There are several ways to financially donate; sending a cheque, online deposit and also bequest a donation in your will. If you or any family members are interested in donating in any way you can find out more by visiting www.cbr.auckland.ac.nz or phoning Laura Fogg, Communications Manager, Centre for Brain Research

Phone: 0064 9 923 1913

Email: cbr@auckland.ac.nz

Thank you to you Shirley for your invitation.

Tracey Larsen

NOTICE BOARD

** AGM **

The AGM will take place on Wednesday 25th March at 6.30 pm in the Life Unlimited Board, 20 Palmerston Street. Financial members will be eligible to vote at the AGM

Show your Ability Expo

The 2015 'Show your Ability' expo will be held at the Claudelands Event Centre on Wednesday 25th February. The event runs from 9 – 3, with both free entry and car parking.

On display will be all kinds of equipment for younger and older disabled people and older persons care equipment.

The Waikato Wellbeing Show

Look out for our stall at the Waikato Wellbeing Show, this is part of the Waikato Show.

It is being held at the Claudelands Event Centre from Friday 10th to Sunday 12th April.

Entry is \$5pp, children under 5 are free.

Subscriptions

Please note 2015 subscriptions are now due. The cost for subscriptions is \$40 or \$20 if you hold a Community Services Card. A subscription form is enclosed. Thank you for your support.

Vitamin D3

If you are interested in purchasing a quantity of Vitamin D3 please contact Carole Stark on 07 827 7695 or email peterandcarole@xtra.co.nz

Manuscript

Please note the newsletter will now be sent out quarterly, the next edition will be sent out in May.

A day of fun at Hamilton Zoo

Dinsdale Lions in conjunction with Hamilton Zoo and Friends of Hamilton Zoo will be holding their **19th annual zoo day** on Sunday 15th March, from 10.00 – 2.00 pm.

Entry is free for people with disabilities and their immediate family/caregiver.

Transport within the city boundaries can be provided if this is registered by the 27th February.

For more information contact Graeme Opie on 07 8252005 or Roger Bell on 027 440 0370.

MS Education

MS Auckland are organising an education session on Saturday 16th May, this will take place in Auckland and speakers will include Wallace Brownlee. Please keep this date free if you are interested in attending this, further information will be available nearer the time.

Oceans of Hope

The Oceans of Hope will be visiting Auckland from the 6 - 12 May. This is a yacht which is currently undertaking the first ever circumnavigation under sail with a crew of people living with MS. It is operated by the Sailing Sclerosis Foundation, a charity registered in Denmark.

The yacht has a fixed permanent crew of three and an ever-changing, international MS crew of six when at sea. In each stopover they give dozens of local people living with MS the experience of sailing aboard Oceans of Hope.

If you are interested in participating in this sailing experience a link is below. The yacht is wheel chair accessible. The only expense would be your transport to Auckland.

You can view the project at their website <http://www.sailing-sclerosis.org> or at their Facebook page <https://www.facebook.com/OceansofHope>

Wheelchairs

MS Waikato has wheelchairs available for loan, for all enquiries phone 07 834 4740.

Thanks to our Sponsors and Supporters



WDFW Karamu Trust • Waipa District Council • The Norah Howell Charitable Trust • Motavation Automotive Workshop • Harcourts Foundation
COGS - Hamilton City, Hauraki, South Waikato & Waikato West • DV Bryant • Cambridge Lions • Anytime Fitness Tristram St
Lochiel Golf Club • Pak n Save Clarence St • The Sutherland Self Help Trust • The Gallagher Charitable Trust

Fundraising

We have some great fundraisers being planned for this year but we do need your help to help ensure their success.

The Michael Ford / MS Waikato Golf Tournament

We are seeking players, sponsors and volunteers for this. The tournament is taking place on Friday 6th March at the Lochiel golf club, if you would like more information or know someone who may wish to receive information on this please call Janet on 07 834 4740 or email janet@mswaikato.org.nz.

This is a stableford tournament with divisions for men, ladies and non-golfers. There will be some great prizes to win and entry includes a sausage sizzle and refreshments on the course. The cost for early bird entry is \$35 pp for registrations received by 26th February. Registrations after this date are \$40.

The event was established 15 years ago by Michael Ford, one of our clients affected with Multiple Sclerosis. It's a great day out and as with all our fundraising the funds raised are kept within our region and used to assist with the provision of our services.

The Entertainment Book

MS Waikato will be selling the Waikato/ Bay of Plenty Entertainment books this year. For only \$60 you will receive thousands of dollars worth of vouchers in our region. The book contains 2 for 1 deals and discount vouchers for many of our restaurants, cafes and entertainment venues. MS Waikato will receive \$12 from each book sold. The book will be available from the 20th April with pre-sales being available from the beginning of March. A sample book will be available in the office to view.

World MS Day Our annual appeal will take place on **Thursday 28th May**

Kawhia Cruise The Kawhia Cruise will take place on **Sunday 1st November**

MARCH 2015						
SUN	MON	TUE	WED	THU	FRI	SAT
1	2 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dusk Till Dawn	3	4 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	5	6 The Michael Ford / MS Waikato Golf Tournament	7
8	9 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	10	11 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	13	14
15	16 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	17	18 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19 MS Support Group Mometewa Te Aroha 10am	20	21
22	23 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	24 ME (Chronic Fatigue) Social Group Meeting Contact Tracey on 834 4745 for details Chartwell, 2pm	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26	27	28
29	30 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	31	MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton			



MSWT EVENTS CALENDAR

APRIL 2015

SUN	MON	TUE	WED	THU	FRI	SAT
			1 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	2	3 Good Friday	4
5	6 Easter Monday	7	8 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	9 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	10 Waikato Wellbeing Show Claudelands	11 Waikato Wellbeing Show Claudelands
12 Waikato Wellbeing Show Claudelands	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dusk Till Dawn	14	15 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	16 MS Support Group Mometewa Morrinsville 10am	17	18
19	20 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	21	22 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	23	24	25 ANZAC Day
26	27 ANZAC Day Holiday Observed	28 ME (Chronic Fatigue) Social Group Meeting Contact Tracey on 834 4745 for details Chartwell, 2pm	29 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	30		

MAY 2015

SUN	MON	TUE	WED	THU	FRI	SAT
31					1	2
3	4 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St, Hamilton MS Support Group Te Awamutu 10am, Dusk Till Dawn	5	6 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	7	8	9
10	11 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	12	13 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	14 ME/CFS Support Group Methodist Church Bader St, Melville 10.30am	15	16
17	18 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	19	20 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	21 MS Support Group Mometewa Matamata 10am	22	23
24	25 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	26 ME (Chronic Fatigue) Social Group Meeting Contact Tracey on 834 4745 for details Chartwell, 2pm	27 MS Exercise Class 10.30am–11.30am Anytime Fitness 56 Tristram St Hamilton	28 Annual Appeal for World MS Day	29	30

MS Waikato Trust, Life Unlimited Building, 20 Palmerston Street, PO Box 146, Hamilton 3240
Tel 07-834 4740, Email mswaikato@mswaikato.org.nz, Website www.mswaikato.org.nz

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