

CONNECTIONS

BRINGING THE AKCEA CONNECT COMMUNITY TOGETHER | EDITION 1 | JUNE 2020

Welcome to your first Akcea Connect newsletter

We're delighted to introduce you to the whole Akcea Connect team, give you some updates on how we're working to keep you safe in lockdown, and a few ideas on how to keep yourself busy and healthy while staying at home.

How we're working to protect you in these challenging times

We want to reassure you that the Akcea Connect team take the COVID-19 pandemic very seriously. That's why we've put in place additional health and safety measures, in accordance with the government, NHS and public health guidance, to help protect you and your family:

- Everyone will now start treatment in the comfort of their home, rather than having to visit the National Amyloidosis Centre (NAC).
- We will call you the day before the visit to check you and your family remain well. If you don't feel well or if we are concerned, we may need to delay our visit.
- We will only bring essential equipment with us when we visit you at home.
- Please provide us with an area to put on our personal protective equipment (PPE: gloves, masks, apron).
- We will advise you how to help us safely dispose of all of non-sharps items and PPE after we leave.
- Our visits will be shorter than usual, but hopefully things will be back to normal soon.
- We will continue to work closely with Professor Gillmore and his team at the NAC to assess the situation and will update you with any changes needed.

"It has been a pleasure to be able to deliver this exciting treatment to patients in their homes via the Akcea Connect nurses. This is particularly true in light of the COVID-19 pandemic when patients do not want to be travelling unnecessarily."

Professor Julian Gillmore,
Head, Centre for Amyloidosis &
Acute Phase Proteins and NAC
Research Lead



IMPORTANT UPDATE FOR NEW PATIENTS:

We don't want anybody who is a new patient to experience any delay to starting treatment. In light of the current pandemic, new starters will have their first treatment in the comfort of their own home. Blood tests will be taken at home, then two weeks later, they will receive their training to administer the first treatment.

If you have any questions please call your Akcea Connect nurse or contact connect@akceatx.com

AKCEA CONNECT®

Meet the Akcea Connect Team



Tina Holmes

Lead Nurse

07880 056004

t.holmes1@nhs.net

Tina has been working in healthcare for over 20 years, and was the first ever Akcea Connect nurse. As part of her role, she liaises with the NAC about your care, and supports the Akcea Connect team.

Tina lives with her partner and two children, and keeps active walking her two dogs.

"As the first Akcea Connect nurse, I have had the privilege of watching the team grow - I absolutely love working in homecare!"



Daisy (Ramune Rutkauskaite)

Nurse Advisor

07762 005788

r.rutkauskaite@nhs.net

Daisy has been a nurse for over 25 years – qualifying in Lithuania where she was born, before joining the Akcea Connect team.

Daisy works in the South, but you might meet her if your dedicated nurse is on holiday.

Daisy is newly married with a very active toddler, and enjoys experimenting with new cookery recipes.



Kariuki Gakura

Nurse Advisor

07917 793384

kariuki.gakuru1@nhs.net

Kariuki has over 28 years of nursing experience, including training healthcare teams in setting up Primary Healthcare programs in developing countries.

Kariuki lives in South Yorkshire with his wife and two sons, and likes cooking traditional food using home grown vegetables and keeps fit by running regularly.



James Dowie

Nurse Advisor

07375 822003

james.dowie5@nhs.net

James has been a nurse for 5 years and supports the South region. He has experience working in cardiology, medical devices, biologics and medical insurance.

James lives in Surrey with his wife and five children, and enjoys going to the gym, listening to 80s rock music and playing the drums.



Beth Sutton

Nurse Advisor

07788 360185

bethany.crighton2@nhs.net

Beth works in the Cheshire region and enjoys working as part of the tight knit, efficient Akcea Connect nursing team.

She is married, with 2 girls, and has a wide and active social circle of friends and family.

Recently, during this period of lockdown, Beth has been enjoying taking part in general knowledge quizzes, becoming quite an expert in movie trivia.



Trudi Jones

Project Manager

07469 571686

trudi.jones3@nhs.net

With 39 years of nursing experience, 22 of those as a nurse advisor, Trudi manages the team of Akcea Connect nurses, sometimes accompanying them on home visits.

She is married with a grown up son, and lives in Worcestershire, enjoying long country walks in the forest with her dog.

Trudi has an active social life, keeping in contact during lockdown with virtual cocktail and cookery parties.

Our contact hours are Monday to Friday, 8.30am - 5.00pm

Tips for living well

The COVID-19 pandemic has made us all more aware of the importance of our health, especially for those with a weakened immune system. While staying at home during the lockdown, there are things you can do, to help get through these uncertain times, and keep your mind and body safe and well.

NHS support to help you

There are a number of useful resources on the NHS website, designed to help you manage any anxiety you may be experiencing, including:



Be Mindful, an online mindfulness course



Sleepio, to help improve your sleep



Chill Panda, that teaches you breathing techniques to help you relax

You can find these, and many more resources here: www.nhs.uk/apps-library
To find the apps above filter by: 'Covid', 'Mental health', 'Sleep'



Stay connected

Whether it's having Zoom calls with friends and family, or simply picking up the phone, it's good for all of us to talk - now more than ever. If you haven't tried a Zoom call yet, now is a great time to start - you can have group chats, do quizzes, and it's good to see familiar faces while we're social distancing. Your Akcea Connect nurse will be more than willing to show you how to participate in a Zoom call if needed.



Keep moving

Make sure you take daily, gentle exercise, to help your joints and muscles to stay mobile. There are a range of stretches, joint rotations and strengthening exercises that can help with flexibility and fitness. Always listen to your body, and only do what's right for you. We will soon be releasing videos demonstrating some exercises.



Try something new

While we're spending so much time at home, this is the perfect opportunity to take up a new hobby. Maybe you always wanted to learn another language, or try your hand at macramé, become a masterchef in your own kitchen or develop a new appreciation for the arts by taking a virtual gallery tour... there are endless possibilities.



Take time to rest your mind

We're all feeling a bit anxious, so take some time to try some relaxation techniques, such as mindfulness, or listening to relaxing music or immersing yourself in a book. While our daily world has got smaller, we have the opportunity to become more observant of things around us, from the beauty of passing clouds or the play of light on the leaves of a tree.



Eat well

Make sure you have a balanced, healthy low-salt diet, with plenty of delicious vegetables and fruit, whole grain carbohydrates and unsaturated fats. Eating meals packed with vitamins and nutrients can help strengthen your immune system, and make you feel better too.

What's coming next...

Stay connected

This newsletter is for you, and is your opportunity to share your challenges, successes and your stories with each other.

What new things have you learnt?

What's the best thing/the worst thing about lockdown?

Tell us something you did that you're proud of

(mastering a particular recipe, for example)

How have you been keeping in contact with friends and family?

We'd love to hear from you, so that we can add your stories to our next newsletter, to help support each other through these strange times.



You can send an email to us at connect@akceatx.com with your story, or talk to your nurse next time they visit.



Get active

We're busy creating some exercise videos to help keep you active while in lockdown. We look forward to sharing them with you in our next quarterly newsletter.

Keep calm and do a word search

POSITIVE HOPEFUL JOY BRAVE
KEEP CALM STAY HOME SAFE KIND
BREATHE COMFORT TOGETHER LOVED

P	Y	R	E	H	T	E	G	O	T
I	O	T	R	O	F	M	O	C	E
E	J	S	Y	G	E	H	A	L	M
T	V	E	I	F	L	R	B	K	O
B	R	E	A	T	H	E	I	P	H
R	Z	S	P	H	I	N	S	E	Y
A	L	O	V	E	D	V	M	N	A
V	M	L	A	C	P	E	E	K	T
E	H	O	P	E	F	U	L	O	S

The Akcea Connect team is always here for you

Whenever you need us, whether you are worried about something, need more information or want to give us some feedback, just pick up the phone. Wherever possible, we will try to be available.

You can find our contact info on page 2, next to our photos. Our contact hours are **Monday to Friday, 8.30am - 5.00pm.**

We look forward to catching up with you at our next home visit.

Your Akcea Connect team