



Touchlines

Support for English-speaking people touched by cancer in France

The Newsletter of Cancer Support France — Association N° W163000037

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PRESIDENT'S PONDERINGS - a few words from Pat Lockett

We have all experienced a strange and challenging time since my last report written in March. I am sure that just like Barry and me, you have concentrated upon staying well and maintaining the requirements of confinement. Keeping in touch with family and friends has been a priority.

All of the above has been true for CSF too. I know all of our Associations have offered continuous remote support to clients, members, volunteers and supporters. At the same time, all events have been cancelled or postponed with the obvious impact on fundraising for this year. Indeed the Cycle for Life in aid of CSF National should have taken place in June but I am pleased to say we have rescheduled it for September and Penny's update is in this edition of Touchlines.

You may recall that I wrote last time about CSF extending its offer of support to any English-speaker in France who is vulnerable or feeling isolated during the health emergency. The promotion of this offer has helped new clients to find us and has prompted contacts from people offering to volunteer. We will continue to offer this extension to our usual work for as long as there is a need.

Much of the usual business of CSF National has continued, with reviews of key documents making good progress. Very soon we will have an updated Guide to CSF, available to anyone who wants to know more about who we are and what we do. I am grateful to Graham Luck for taking the lead on this project.

Members of the National Bureau have also not been idle, working on documents that will help all CSF Associations in the areas of training, public relations and marketing. Enhancing the website has been part of these developments; Dave Wilson (PR) has been working with Frank Parkinson (Webmaster) to create a Friends of CSF page where high-profile people are giving testament to our work. Dave Wilson (PR) tells us more about our new 'friends' in this addition. Please take a look... you may be surprised who you find there!

As I write, we have entered the next phase of de-confinement and are enjoying a little more freedom. This in turn, is prompting Associations to begin to plan for a return to client visits, holding training and fundraising events. Carol Quinlan (Training Liaison) is developing health and safety guidance to help our Associations prepare to meet once again whilst ensuring all social distancing measures are in place.

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REGIONAL ROUND-UP

DORDOGNE EST & LOT - Submitted by Anna Shackleford

It has been a strange but largely peaceful few months here in the Lot, as elsewhere. Being a mainly rural department, we have been very lucky in that we have had relatively few reported cases of COVID-19 and only a small number of deaths. Our Association, along with many others, were pleased to participate in the extended service CSF offered to all Anglophones who may have experienced problems due to the isolation occasioned by the lockdown and in addition, our clients have reported an excellent uninterrupted service regarding any medical treatments or procedures scheduled for their condition.

Administratively, we have held two Bureau and Council meetings online using GoToMeeting and we have all felt a sense of common purpose and comradeship seeing each other and discussing our way forward as events changed around us. As President, I have kept members abreast of the latest government communiqués, using the excellent summaries that the British Embassy in Paris issued after each Presidential or Prime Ministerial TV broadcast and feedback was that these were much appreciated.

Our most recent Council meeting was on 16th June and we have begun to make tentative plans for events in the autumn. All of these will be subject to cancellation or postponement if rules regarding COVID-19 change but we are hoping to hold a 'Bad Hatters Tea Party' in September with a book stall and tombola so that we can meet up again with our members and supporters in a convivial atmosphere. Details of the date and venue will be spread via email and social media once arrangements have been firmed up. In October, we are hoping to hold the breast cancer discussion group, which was scheduled for March and which, obviously, had to be put on hold. And, all things being equal, we will resume our monthly 'CSF at the Caff' drop-in sessions at local cafés – again details will be posted after the summer.

We wish all readers a happy, safe and healthy summer in our cautious return to life after lockdown!

LANGUEDOC - Submissions contributed by Alison Kane, Jenny Guest and Hilary Galea

BUSINESS CONTINUES – ALTHOUGH NOT QUITE AS USUAL

From the beginning of the COVID-19 confinement period in mid-March, CSF-Languedoc were very conscious of the worry and isolation felt by many members. Because of this, the Council took actions to keep their membership, as well as the wider Anglophone community, informed about new COVID-19-related government announcements in regular bulletins. The bulletins also included tips on health, well-being, keeping up morale, local news and general advice on coping with confinement. By early April, these bulletins were also being published in *Languedoc Living*, our main regional on-line English journal.

Our usual lines of client support continued throughout the confinement period, albeit via phone and video conferencing rather than face-to-face. Also, in line with the decision made by CSF National, emotional and practical support was also offered to those touched by COVID-19.

KEEPING IN CONTACT WITH CLIENTS DURING CONFINEMENT

Our Drop-In days, usually held on the last Thursday of each month, have been suspended since March. After gathering feedback from regular Drop-In attendees as to how best to compensate for the loss of these monthly gatherings, it was felt that ZOOM meet-ups were not a popular option. However, many clients have found that being in more regular contact with their family and friends, often via social media, has proved to be a compensation. Our Active Listeners continue to keep in regular touch with their clients who also receive a monthly email from the Drop-In team, reminding them that our Helpline is always available if they would like to organise a chat with someone.

Extra support, along with the emails, has included a link to a Breathing and Relaxation session, kindly offered and recorded by Erzszi Lyne de Ver for any CSF-Languedoc members, especially those who have been suffering from added anxiety during these difficult times. And in May, members of our Drop-In kitchen team provided a range of recipes for people to try at home, including some that have proved popular at Drop-In days. In June, which would normally be the

LANGUEDOC - continued...

last Drop-In before the July/August summer break, we are, just for this once, attempting a video get-together for anyone who wants to 'drop in' for a "Hello", plus an on-line gentle yoga session given by one of our therapists.

EUROPEAN CANCER PATIENT COALITION WEBINAR

As a member of the European Cancer Patient Coalition (ECPC), CSF was invited to register for a Webinar on the 9th June entitled: *There is Life after Cancer: Putting an end to the Discrimination*.

Seven speakers participated in the event including MEPs, patient advocates and expert members of ECPC, whilst 170 people registered to listen-in.

Thanks to improvements in cancer diagnosis and treatment, the number of cancer survivors is increasing (estimated to be 12 million in 2018). Cancer Survivors have to overcome not only the psychological impact of treatment but may also face workplace marginalisation and discrimination when accessing financial services including mortgages, loans and insurance.

A special focus of the webinar was the ECPC project: *the Right to be Forgotten for Cancer Patients* which has been named as one of the European Commission's priorities.

The value of survivors being able to regain important aspects of their life before cancer and, finding pathways to a new life going forward, has been recognised. Many, however, have faced discrimination in the workplace. While those in paid employment have certain rights offering lifelong protection, the self-employed do not have the same rights. Longer treatment times means that cancer patients might be regarded as a risk and the self-employed also face the stress of 'no work - no pay'. Travel is taken for granted as part of working life and for leisure but finding travel insurance can be a minefield.

Petra de Sutter MEP, explained about the European Commission's *Beating Cancer Plan*: A European solution based on a legal framework is needed, though currently countries lack policies regarding survivorship. Only in France, Belgium and Luxembourg have laws been passed which recognise the *Right to be Forgotten* for cancer patients.

More research is needed to build an evidence-base to show the challenges faced by cancer survivors and to record discrimination faced by cancer survivors; whether inequalities and disparities in the workplace, when accessing financial services (mortgages and loans), being forced to pay higher premiums for private health insurance as well as the additional burden of the associated psychological challenges. A comprehensive evidence base will inform focused solutions.

ECPC MEMBERS ARE INVITED TO SUBMIT EXAMPLES OF THEIR EXPERIENCES OF DISCRIMINATION

CSF members are invited to send information about their own experiences on this issue to Jenny Guest at jenny.csflanguedoc@gmail.com who will coordinate responses and forward them to the ECPC.

Following this evidence gathering, the Plan will be launched at the end of this year. The Plan will take an holistic approach from diagnosis to survivorship and will include loved ones as well as patients.

You can access the ECPC website here: -

https://ecpc.org/wp-content/cache/page_enhanced/ecpc.org/index_ssl.html_gzip

View the Webinar at: -

https://ecpc.org/wp-content/cache/page_enhanced/ecpc.org/policy/the-right-to-be-forgotten-a-new-research-project/index_ssl.html_gzip

You can also download the ECPC *Right to be Forgotten* fact sheet on the last link.

But there were other concerns too, relating to the support needed for the volunteers themselves: -

- Some Active Listeners, without designated clients, were feeling 'redundant'. What can we do, if not supporting clients?
- How can skills be maintained if all Active Listener's on-going training is cancelled for the foreseeable future?
- How can we deal with the loss of Drop-Ins for clients and Active Listeners? What sort of remote activities could maintain that feeling of cohesion?
- How can we keep a feeling of being part of the CSF-Languedoc team?

The weekly Bulletin answered many of these questions but information alone could not address the threat to the cohesion of the CSF-Languedoc community. So in the light of this feedback, the CSF-Languedoc training team has devised the following activity designed to re-energise volunteers in their support of clients.

TASK REASSIGNMENT

Those volunteer Active Listeners who had several clients have had some of their work reassigned to others who were feeling redundant. Most Active Listeners signed up to volunteer for CSF-Languedoc in any capacity in which they could be useful; the most important thing was for them to feel that they were contributing, so jobs outside the Active Listener remit have also been given to Active Listeners – and have been accepted with enthusiasm and relish.

ACTIVE LISTENER ON-GOING TRAINING ON-LINE

On 16th June, we had our first on-line training session for Active Listeners. Eighteen people joined a one-and-a-half hour ZOOM meeting (CSF-Languedoc now has its own ZOOM account) for an animated and immensely useful discussion on hospital practices (which vary by hospital and are subject to frequent, sometimes daily, change, responding to COVID-19), training options and topics and how to keep our skills fresh. Whereas we normally meet three times a year for on-going training, all Active Listeners actively wanted more frequent sessions like this, (loo and refreshment breaks included!)

The session was chaired by Karen Powell, our Lead Trainer, with an agenda and supporting papers shared in advance. The session included time to share experiences and feedback and laid out an agenda for future sessions. By consensus, the next priority (to be run as soon as possible, preferably before the end of June), was a review of Active Listener and client boundaries in light of COVID-19.

OBSERVED BUDDY PRACTICE

After a month of not doing any active listening, 'skills decay' sets in. It's surprising what you forget and it's easy to develop bad habits. Buddy practice helps and On-going training days for Active Listeners (3 times a year) always include half a day on skills refreshment where Active Listeners pairings are observed by a third party. However, as part of the demotivation that the lockdown engendered, buddy practice had become infrequent, losing discipline and focus. On-going training days had been cancelled. So the training team has come up with a method which we hope will work well.

New Buddies have been assigned (due to some Active Listeners moving on, or joining the team) and will be in contact at least fortnightly (preferably weekly) to practice their skills: 20 minutes listening and 10 minutes reviewing (Active Listeners are encouraged to set a timer for this). Once, every three months, this Buddy practice will be 'observed' by a third party who can offer objective feedback. Active Listeners who feel their skills to be particularly rusty were invited to contact Lead Trainer, Karen Powell, to refresh them in advance of re-booting their buddy practice. Buddy pairs are to choose their own preferred communication platform (ZOOM, WhatsApp, Facebook Messenger, Facetime, Skype or phone call). This provides audio-visual and audio-only options with which any observer can join in. Active Listeners are also encouraged to set their own skills agenda for different practices; one week it might be open questions and testing understanding, another, exploring silence in Active Listeners practice.

To support this, an 'Active Listening skills short guide' and 'Buddy practice pointers sheet' have been written and shared as a reminder and check-list for the Active Listeners .

LANGUEDOC - continued...

DEMONSTRATION VIDEOS

Active Listeners have been circulated with Karen Powell's one-hour presentation recorded by the World Alliance of Pituitary Organisations (WAPO) which offers a useful summary of the Active Listener method.

Two of our most experienced Active Listeners are planning to create demonstration videos to exemplify good (and bad) practice for Active Listeners to watch regularly to remind themselves of what they should be doing. Also on another front, a demonstration video of yoga for clients is being planned; the possibilities to create on-line demonstrations of other alternative exercise regimes for clients are plentiful...

Other training that we traditionally offer (Induction days for new volunteers and the three-day intensive Active Listeners training course) is temporarily on hold, although we have begun to think about how the elements of induction could be offered online.

We have surprised ourselves by being excited by the challenges of rethinking our support for clients and volunteers; it turns out that being in a tight corner sparks the imagination and focuses the mind. We would love to hear from other regional groups what you have done; new ideas will be embraced enthusiastically.

FRIENDS OF CSF - Submitted by David Wilson, National PR

CSF now has a number of high-profile 'Friends'. It has been the plan for some time to find some well-known English-speaking individuals who would recommend what we do. This will, we hope, help to encourage people to look at the services we offer. In due course, some of the individuals might want some closer involvement with CSF, but this is by no means obligatory, and we are extremely grateful for their support.

Our first Friends are: -

- Anthony Daniels - actor, famous for playing robot C-3PO in Star Wars
- Carol Drinkwater, who played Helen Herriot in All Creatures Great and Small and is now well-known for her books on running an olive farm in Provence
- Jess Harrison, 2 times world team triathlon silver medallist and 5 times French elite champion
- Chris and Moira, lifelong professional musicians - Chris is leader of the Temperance Seven and Moira is a former Professor at the Royal Academy of Music
- Martin Walker, novelist, author of the popular Bruno, Chief of Police detective series set in the Périgord
- Rag Mama Rag, one of Europe's finest country blues acts
- The Friends are shown on a special page on the CSF website - <https://cancersupportfrance.org/csf-friends>



Anthony Daniels



Carol Drinkwater



Martin Walker



Jess Harrison



Chris & Moira



Rag Mama Rag

THE CSF ANNUAL CYCLE FOR LIFE
WEDNESDAY SEPTEMBER 23RD TO SATURDAY SEPTEMBER 26TH 2020
FOLLOWING LA FLOW VELO THROUGH THE CHARENTE

Submitted by Penny Parkinson - sud-penny@cancersupportfrance.org

Come and join us as we cycle through glorious countryside enjoying the mellow autumnal colours of September ... and, maybe a little light mistiness! This year's route follows *La Flow Velo*, starting at lunchtime from Rochefort and stopping at pretty St Savinien, boozy Cognac and the hilltop old town of Angoulême with a gentle ride around this area on Saturday morning, finishing with the traditional 'Welcome' lunch to thank all our cyclists and supporters.

You'll be pleased to learn that the Participant's Pack is now available. This contains not only details of the route but also lunch and water stops, possible accommodation from campsites to hotels, as well as practical information on transport, bike safety, additional precautions due to COVID-19 and so on. We'll be adding restaurant information and arranging group evening meals for those who would like to join in nearer the time. The restrictions during the '*crise*' mean that restaurants are not yet able to consider bookings.

Do keep an eye on our CSF website for up to date information on the *Cycle for Life* here: -

<https://cancersupportfrance.org/cycle-ride-confirmed-september>

There, you will also find the link to our Facebook page which will be updated with progress. Publicity is in hand and we are already attracting new cyclists from this lovely area of France. You will also find a link to the *Alvarum* page which makes collecting funds through sponsorship quite simple and has the advantage of giving French tax payers the appropriate tax receipt.

If you are interested in taking part, or have any queries, then do contact Sasha on admin@cancersupportfrance.org She will ensure that you are kept fully informed as planning progresses and answer any queries.

DON'T FORGET... there is no need to cycle the whole route, come and join for a day or even for half a day or simply take a short while to encourage the cyclists as they meander along the route, raising awareness of what CSF is about. We'll be delighted to see you!with Chris



Some of the photos and reflections of our 2019 *Cycle 4 Life*.

Top left: - Ready to start on d 5

Top right: - Lunch by the sea with Chris Dowd

Bottom left: - The fountains of Perpignan as a backdrop

WOMEN OVER 45 LESS LIKELY TO ATTEND SMEAR TEST DESPITE 50% OF CERVICAL CANCERS BEING DIAGNOSED LATER IN LIFE

An article by **Sophie Gallagher** published on 7th November 2019 in *The Independent*

The number of women attending regular smear tests steadily declines after the age of 45, according to a new study, despite half of cervical cancer diagnoses occurring in women over 49.

Cervical cancer is one of the most preventable types of cancer but the findings from the University of Michigan cancer centre highlight the need for women to continue attending appointments post-menopause for early detection to be possible.

The new study, which appeared in the journal *Preventative Medicine* and analysed data from around 80,000 participants in the USA, found screening rates drop in certain sub-populations of women, particularly those between the ages of 49 and 65.

Women in rural communities and those with lower levels of education were also less likely to regularly attend their screening.

In the UK, the **NHS** says all people with a cervix between the ages of 25 and 64 should go for regular cervical screening – they will get a letter in the post inviting them to do so.

Unless your doctor requires you to be tested more regularly, you will have a smear test every three years between the ages of 25-49 then every five years between 50-64. After the age of 65 you will only be invited if one of your last tests presents abnormal results.

Cervical screening checks for abnormal cell changes in the cervix or the presence of HPV (the human papillomavirus).

A routine programme of vaccination against HPV has been offered to girls in UK secondary schools since 2008 and boys since September 2019. But older age groups have not had this, which scientists say places even greater emphasis on screening.

Professor Diane Harper, senior study author, said: *“Early detection is key to preventing invasive, devastating and potentially fatal cases of cervical cancer. From a public health standpoint, screening of women under 30 is considered to be the least effective investment of resources, because cancer tends to develop in middle age. Meanwhile, if a woman is screened after age 42, there is an 8 in 10 likelihood no cancer will be detected at her next screening a few years later -- meaning they’re a vital way of catching problems early.”*

This study supports previous research from **Cancer Research UK** which found women who failed to attend screenings after their 50th birthday were six times more likely to end up with cervical cancer.

The number of eligible women aged 50-64 who attended cervical screening appointments dropped from 81% in 2003 to 77.5% in 2013.

SMEAR TESTS FOR CERVICAL CANCER COULD BE REPLACED BY DIY HOME SAMPLE KIT

An article by **Jemma Crew** published on 5th November 2019 in *The Independent*

A non-invasive urine test could be used by women to detect their risk of developing cervical cancer without needing to visit the doctor.

Researchers have developed a way to identify pre-cancer lesions by analysing urine and vaginal samples that could be collected by women in the comfort of their own home.

The ‘self-sampling’ test proved popular with women taking part in the study, meaning it is likely to improve participation in cervical screening programmes if made widely available, they believe.

Dr Belinda Nedjai, director of the Molecular Epidemiology Lab at Queen Mary University of London, said: *“The initial use of self-sampling is likely to be for women who do not attend clinic after a screening invitation and countries without a cervical cancer screening programme. In the longer term, self-sampling could become the standard method for all screening tests.”*

“The study indicated that women much preferred doing a test at home than attending a doctor’s surgery.”

Resourced by the Editor



We remember our
Founding President,
Linda Shepherd
1953-2017

Also [Here](#) to Help...

Cancer Support France are proud to be in partnership, affiliated to or supported by the following associations and groups: -

In partnership with:

En partenariat avec:



www.prostatecanceruk.org



www.be.macmillan.org.uk



Beating blood cancer since 1960

www.bloodwise.org.uk



www.breastcancersupport.org.uk



www.thebraintumourcharity.org



www.cancerresearchuk.org



www.pancreaticcancer.org.uk



www.targetovariancancer.org.uk



www.bowelcanceruk.org.uk

If you have been affected by any of the issues raised in this newsletter, please don't hesitate to contact your regional CSF branch. All telephone numbers and email addresses can be found on the back page of TOUCHLINES. *Ed.*

USEFUL INFORMATION

Association Siège Social

Espace Clément-Marot
Cancer Support France, Box 25
Place Bessières, 46000 Cahors

National HELPLINE

Telephone: 0800 240 200 (FREE from a landline)

(Your call is taken on an answerphone and is free from a landline - there is a short message in English - we will reply to you as soon as possible and normally within 24 hours)

Useful Contacts

President: Patricia Lockett
president@cancersupportfrance.org

Treasurer: Jean Winter
treasurer@cancersupportfrance.org

E-mail: helpline@cancersupportfrance.org

Website: www.cancersupportfrance.org

forum.cancersupportfrance.org

CSF FORUM - Visit the CSF website and take a look at the FORUM, packed full of information and interesting conversations - maybe even meet new friends...

REGIONAL GROUPS

Alpes-Maritimes (06; 83)	Angela Anderson (Mobile)	07.68.38.74.70 06.48.50.36.46	cancersupport06@gmail.com
Bordeaux & Region (33)	Marissa Raymond	0800 240 200	bdx-helpline@cancersupportfrance.org
Charente-Maritime (17)	Richard Smith	06.79.16.60.83	csfcharentemaritime@gmail.com
Charente Plus (16)	Denise Bloom	06.45.35.32.30	csf.charenteplus@gmail.com
Deux-Sèvres (79)	Denise Langford	06.40.77.27.35	deux-sevres-president@cancersupportfrance.org
Dordogne Est & Lot (24Est; 46)	Anna Shackelford (24h Helpline)	06.35.90.03.41	delot-president@cancersupportfrance.org
Dordogne Ribérac (16; 24)	Paula Cragg (Helpline)	05.45.25.55.28 06.43.67.86.11	csfriberac@gmail.com paulacsf16@icloud.com
Dordogne Sud (24; 33)	Bob Kennedy (Mobile)	05.53.23.29.17 06.03.39.24.33	dordsud-treas@cancersupportfrance.org
Gascony (31; 32; 65)	Jayne Ray (mobile)	05.62.31.63.40 06.27.69.62.28	gascony-contact@cancersupportfrance.org
Haute-Vienne (87; 23; 19; 36)	Sue Ware	0800 240 200	helpline@cshautevienne.org
Languedoc (12; 34)	Jen Glayzer Helpline	04.67.44.87.06	president.csflanguedoc@gmail.com
Lot-et-Garonne (47)	Cindy Sheppard	06.70.64.68.82	helpline@cancersupportfrance.org
Lyon (69)	CONTACT NATIONAL	0800 240 200	helpline@cancersupportfrance.org
Nord (14; 22; 27; 29; 37; 50; 53; 56; 61; 76)	Jean Winter	0800 240 200	nord-president@cancersupportfrance.org
Paris & Ile-de-France (75, 77, 78, 91, 92, 93, 94, 95)	Deborah Lillian	0800 240 200	paris-idfpresident@cancersupportfrance.org
Provence Gard (13; 30; 84)	Tim Forster	04.66.81.18.58	csf.provencegard@gmail.com
Sud de France (09; 11; 66; 81; 82)	Phil Mercer	07.80.38.00.65	sud-president@cancersupportfrance.org
Vienne (86)	Jacque Kelly	0800 240 200	vienne-president@cancersupportfrance.org

Touchlines

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touchlines@cancersupportfrance.org