

SEPTEMBER 2020



Behçet's Patients Support

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MATTERS

In partnership with the NHS and Behçet's UK

Helping people with Behçet's live well.

"BPS Matters" is published by Behçet's Patients Support.

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COVID -19: INFORMATION

- Behçet's Patients Support continue to work with Behçet's UK to provide non-medical support to their patients and members. Websites of both organisations have been updated to provide information about COVID-19 and what support is available:

<https://behcetpatients.org.uk/covid-19-information>

<https://behcets.org.uk/coronavirus-covid-19/>

COVID -19: PATIENT CONTACT

- Continuing to support patients by email, text and telephone.
- Support Coordinators continue to work flexibly to meet the non-medical support needs of patients.
- Following up patients who have 'clinic' appointments- contact from the Support Coordinator much appreciated by patients.
- Patients feel connected to the Behçet's service and Behçet's community by their contact with the Support Coordinators.
- Providing low-level anxiety support for patients who have not gone out yet and who are worried about either going to shops, work etc.

GOOD NEWS:

- A Patient has been awarded a back pay of £21,000 from the Department for Work and Pensions.
- Regular weekly contact with NHS Centre Psychologists (London & Liverpool) to discuss and refer patients as necessary to each service.
- Supporting patients who are having career changes or starting University.
- Supporting and helping patients with their Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) applications. Documents mailed via clinics to Support Coordinators.
- Obtaining a disabled parking space for a patient outside their house.

- Supporting patients through telephone conference PIP application assessments
- Recipes and nutrition information published in Behçet's UK Newsletter are well received by patients.

COVID -19: TRENDS

- Support Coordinators are receiving a high number of calls from patients, who are feeling lonely, just for a chat. Support Coordinators retain a list of these vulnerable patients to check in with on a regular basis.
- Increase in number of patients with employment/COVID-19 related queries and patients who are confused over shielding.
- Increasing number of queries about going back to work and school and what support is available from Behçet's Patients Support.
- Department for Work and Pensions offering patients telephone renewal assessments without the need for application paperwork

COVID -19: LOCAL SERVICES

- Obtaining support via local Social Services for patients: including
 - securing food parcels, booking online Supermarket delivery slots, Meals on Wheels, food bank deliveries & NHS Volunteer Responders contact.

Team Working:

- Members of the team (John & Jean) took part in the "Behçet's Run for Rare" Challenge. Jean has raised over £500 and John over £375 😊; to date over £10,000 has been raised in total for Behçet's UK. <https://behcetsuk.org/b4b-r4r/>
- Articles published in Behçet's UK Newsletter. Focusing on positive aspects of "living and working with Behçet's".
- BPS Team support, invaluable support to each other during these difficult times.
- Online survey designed for the London Centre to obtain feedback about the impact of COVID-19 on Behçet's patients; <https://www.surveygizmo.eu/s3/90267605/BEH-ET-S-CENTRE-COVID-19-Patient-Survey>