

Press Release: Lyme Disease UK launch national awareness campaign - Wake Up to Lyme

For immediate release

May is Lyme Awareness Month

World Lyme Day on May 1st, marks the beginning of a month of Lyme awareness projects and activities around the world. Lyme awareness month is widely embraced in many countries, with fundraising and awareness events taking place and the lighting up, in green, of major international landmarks.

This year **Lyme Disease UK** are participating by launching a **'Wake Up to Lyme'** campaign. The aim is to raise awareness of how people can prevent Lyme disease by protecting themselves from tick bites, correct tick removal techniques and how to recognise the early symptoms of Lyme disease. The campaign also aims to stress the importance of early treatment for anyone who experiences the characteristic bull's-eye rash or who becomes unwell following a tick bite.

Lyme disease UK will be sending posters and leaflets to parks, outdoor recreation areas, GPs, pharmacies, schools and youth groups to try and limit the number of new infections this Summer and make sure that people enjoy the countryside and great outdoors safely.

The need for greater awareness of Lyme disease

It is vital to educate people about Lyme disease, because it is often misdiagnosed. Early symptoms can include a bull's-eye rash, fever, headaches and fatigue. If the disease is left untreated it can result in joint, heart problems, chronic pain, neurological/cognitive problems to name a few. Treatment is more likely to be effective if Lyme disease is diagnosed early. Awareness is crucial as people need to learn how to protect themselves, their families, and their pets from this potentially dangerous disease.

Public Health England estimates that there are around 2,000 - 3,000 new cases per year whereas Caudwell LymeCo charity and Lyme Disease UK estimates that there could be as many as 45,000. There is a huge discrepancy in estimates, highlighting the fact that the true number is unknown. The fact is, thousands of people will be infected this year and are many are likely to go untreated which can leave people disabled or misdiagnosed with conditions such as chronic fatigue syndrome, depression, fibromyalgia, Alzheimer's and multiple sclerosis. Cases are growing by 65% per year worldwide and without intervention, Lyme disease is estimated to be an official epidemic by the year 2028.

Find out more at www.wakeuptolyme.com where you can request awareness information, join in on social media using #wakeuptolyme and @uklyme or donate to Lyme Disease UK. You can also learn more about the complexities of Lyme disease testing, diagnosis and treatment at www.lymediseaseuk.com.

Notes for Editors

Growing political and media interest in Lyme

Lyme disease has been attracting increasing political and media attention over the past couple of years. This has been reflected in LDUK's increasing online support group membership (currently over 6000 people). Recent political developments include:

- An All Party Parliamentary Group was formed by MPs last month <http://lymediseaseuk.com/2017/03/18/all-party-parliamentary-group-update/>
- See question to Theresa May regarding Lyme disease on March <https://www.youtube.com/watch?v=digEOwKBqAs>
- The Government has commissioned three independent reviews (looking into testing, treatment and transmission of Lyme disease in the UK) and initiated the creation of NICE guidelines for the illness. Due for completion in 2018.
- Lyme Disease will be debated in the Scottish Parliament following the motion below achieving cross party support **'Lyme Disease, We Need to Do More' 22/03/17**

What is Lyme disease?

Lyme disease is caused by a spirochaetal bacteria from the genus Borrelia. It is the most common human tick-borne infectious disease in the northern hemisphere and there are multiple strains of the bacteria. It is endemic in many parts of the United Kingdom, particularly in woodland or heath-land areas as well as urban parks and gardens. Around 1,000 serologically confirmed cases occur in the UK each year, however Public Health England state that the true number could be around 3,000 per year. Caudwell Lyme Disease and LDUK estimates the true figure could be far higher and closer to 45,000 cases per year.

Lyme Disease UK

Lyme Disease UK is a not-for-profit patient support organisation, run by volunteers. We are the largest patient support network in the UK and we have over 6000 members in our Facebook group. We are stakeholders in the UK Lyme disease guideline writing process which is currently being conducted by NICE. We also work with other Lyme charities, politicians and journalists to raise awareness and push for change in the way Lyme disease is handled in the UK. More recently, we have been approached by National Health Service trusts to give presentations and also by schools.

Our mission is to prevent any more UK residents from facing the devastating consequences of being misdiagnosed and untreated for Lyme disease. By working to ensure

1. All front line medical staff in the UK to be aware of Lyme disease and at least one doctor in each team to have completed the RCGP online course on Lyme disease. At the moment only about 2% GPs have completed it.
2. Every UK household to be aware of the risk of tick bites and Lyme disease and to understand prevention methods and symptoms to look for.

3. Provide support and knowledge to every single UK resident who is infected in 2017

Patient stories and photos available.

Please send links to any published stories if you wish us to share them via our social media channels.

Facts and stats are available in our Media Centre here:

<http://lymediseaseuk.com/2017/01/16/facts-and-stats/>

Media interest in Lyme Disease

There has been an explosion of media interest in Lyme Disease in recent months, particularly following **John Caudwell, Yolanda Foster, Ally Hilfiger, Martine McCucheon, and just last week, golfer, Jimmy Walker** talking publically about their diagnosis and becoming involved in raising awareness. Our members regularly appear in the national press and on TV. We can provide a list of links to articles and TV appearances if this would be of interest. Please find a couple of examples below, further patient stories can also be found on our website (<http://lymediseaseuk.com/category/patient-stories/>).

Son of Nigel Haworth, celebrity chef career cut short - Daily Mail, Feb 17

<http://www.dailymail.co.uk/news/article-4214600/Son-Nigel-Haworth-career-cut-short-Lyme-Disease.html>

LDUK member speaking on BBC news last week

<http://lymediseaseuk.com/2017/04/03/bbc-news-lyme-disease-simone-sheppard/>

International examples of landmarks being lit up green for World Lyme Day:

Niagra Falls <https://www.youtube.com/watch?v=Y13V9SbxZLU>

Alabama State Capitol Building

<http://www.prweb.com/releases/2016/05/prweb13392078.htm>

Bank of America, Texas <https://www.lymedisease.org/touchedbylyme-texas-lyme-vigil/>

Contact Details

Lyme Disease UK is willing to connect with journalists from all media and to help out with features on Lyme disease. We can put you in touch with Lyme disease sufferers, doctors and other experts to aid your work. Some of our spokespeople can be found here <http://lymediseaseuk.com/2017/01/16/spokespeople/>

Contact the press office: media@lymediseaseuk.com

Website: www.lymediseaseuk.com

Facebook: facebook.com/lymediseaseuk

Twitter: [@uklyme](https://twitter.com/uklyme)