

## Aims of the Lafora Dogs Support Group

Aims	How?
<p>Providing a central hub for information for people who either think their dog might be suffering, has just been diagnosed or are concerned that they be in the future or etc. This includes details of what to expect, advice on management and the possible impact of dietary adjustments.</p>	<p>Via our:</p> <ul style="list-style-type: none"> <li>• <a href="mailto:laforadogs@btinternet.com">laforadogs@btinternet.com</a> email address,</li> <li>• the new <a href="http://www.laforadogs.org">www.laforadogs.org</a> website</li> <li>• email newsletter - send a request to email address above</li> <li>• Lafora subtopic at <a href="http://www.dachshundforum.co.uk">www.dachshundforum.co.uk</a></li> <li>• Links to and from other relevant sites, e.g. various websites focusing on Canine Epilepsy, etc.</li> <li>• Via telephone conversations</li> </ul>
<p>Collecting details of Lafora dogs and their owners, in order to provide a database of dogs which should be of beneficial for any further research.</p>	<p>We ask for address and contact details, dogs name, age, sex, date of onset, date of birth and death, details of the condition symptoms and medications.</p> <p>We <u>do not pass</u> on any personal information without asking permission first. I started off by asking for pedigrees too, but aware of the sensitivities, this is no longer a requirement, unless the owner wants to send it to me. I do not share information about any dogs that have appeared more than once in any pedigrees I've seen.</p>
<p>Offering support where necessary for emotionally traumatized owners, who feel the need to be in touch with others who have faced the same challenges</p>	<p>Providing a confidential 'matching service' - using the database and knowledge of the owner gleaned through email and phone conversations, where owners are willing to provide informal counseling advice ,on the understanding that this is an informal basis and does not constitute professional advice.</p>
<p>Raising awareness of the condition in a positive context, whilst seeking to avoid inaccurate press reports and maintaining the popularity of this wonderful breed.</p>	<ul style="list-style-type: none"> <li>• Providing news via the email newsletter to members to help them see that 'something positive is happening'</li> <li>• Informed and informative articles on the website and in pdf format to help people understand the background and complexities faced, e.g. explanations of the genetics involved, template letters for owners to use to write to puppy owners where their dam or sire has been diagnosed with Lafora</li> </ul>