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# To Researchers, A Call for Finding Cure for Amyloidosis

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In tribute to the soul of my wife that passed away last Saturday 19/5/2018 after ten months of suffering and struggling with a disease or a group of diseases called amyloidosis.

It is a rare disease that occurs when a protein called Amyloid builds up in the patient organs [1]. Amyloid is abnormal protein that is formed in patients bone marrow and can be deposited in any tissue or organ. It can affect the heart, kidneys, liver, spleen, nervous system, stomach or intestines, but in case of my wife the protein affects the tongue, buccal mucosa, pharynx and vocal cords. Thus, the consequences were gradual loss of voice and difficulty to masticate and swallow even soft meals. This was developed to severe loss of weight and muscle wasting.

Unravelling diagnosis seems very difficult, if not impossible, because high level of protein in urine could be referred to proteinuria or abnormal level of bilirubin. Organ enlargement may be classified as usual organomegaly. Diagnosis is confirmed by tissue biopsy. One of the professors who examined my wife reported: "a case of macroglossia, normal thyroid function, elevated serum amyloid A protein, possibly amyloidosis, the patient cannot eat, with difficulty in breathing, kindly arrange for partial glossectomy with histopathology". However the surgeon refused to conduct this glossectomy.

Amyloids are aggregates of protein that become folded and stick together forming fibrils. In the human body, amyloids have been linked to the development of various diseases. Pathogenic amyloids form when previously healthy proteins lose their normal physiological functions and form fibrous deposits in plaques around cells which can disrupt the healthy function of tissues and organs. Amyloid have been associated with a lot of diseases without being by necessity the cause of such diseases is the reason for amyloid association diseases are unclear. In some cases the deposits physically disrupt normal tissue architecture leading to dysfunction and cell death [2-3].

Chemically amyloids are formed of long chain unbranched fibers characterized by a cross-beta sheet quaternary structure in which antiparallel chains of ß-stranded peptides are arranged in an orientation perpendicular to the axis of the fiber, such cross-beta fibers could be best identified by X-ray diffraction [4].

There are about 30 different types of amyloidosis, each due to specific protein misfolding. Some are genetic while others are acquired. According to Mayo-clinic no cure to date, however treatment depend on the type of amyloidosis that is present. Treatment with melphlan followed by a stem cell transplantation has showed promise in early studies and is recommended for early stage I and II AL amyloidosis. However only 20-25% of people are eligible for stem transplant. Chemotherapy and steroids with melphlan plus dexamethasone is the mainstay treatment in AL people not eligible for stem cell transplant [5-7].

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