Beat: Health

Death by paralysis: the ALS sufferer´s fate

Emerging therapy provides hope

Chicago, 06.03.2020, 17:49 Time

USPA NEWS - Your body has stopped responding. Physical tasks you once did with ease have become difficult. Soon, you are in a wheel chair, then your voice stops working as the paralysis spreads. Trapped in your body, unable to interact with the outside world, you wait for your struggling lungs to stop.

This is not a nightmare: this is one reality of amyotrophic lateral sclerosis (ALS). Sufferers of the disease live an average of two to five years after diagnosis. As the nerves in the spine and brain which control their muscles die, the musculature of their body atrophies and saps their movement and strength.
There is no cure for ALS, and only a limited number of treatments which slow its progression. For families of sufferers it is agonising, watching a slow death take their loved ones.
Beth Robertson remembers her husband, Tim, and his selfless efforts to keep the family living over the 12-year downward spiral of his ALS.
“He let us continue to lead our lives. It helped that I kept my job teaching...ALS dominated every aspect of our lives...Every time he went into a little slump. Every time you´d see a decline. Where he sat on the back deck watching me garden when he couldn´t garden with me anymore,“ Beth says.
“There´s no blessing in this. It´s a tough journey,“ she admits. “Even though we had more time and Tim was fortunate to see his children graduate from high school, it´s hard to give a positive final message that is honest.“

Lives cut short
For many ALS patients, time is cut even shorter than it was for Tim and Beth. As such, research in new medicine cannot come quickly enough.
“For some individuals, from diagnosis of their very first symptom to death can be six months,“ says Dr Janice Robertson a specialist in ALS operating out of the Toronto Western Hospital Research Institute.
“Fifty per cent of people die within 18 months; 80 per cent of people die within two to five years...And that´s why time is of the essence, it´s not only for the future, it´s for the people living now with this disease“ Dr Robertson explains.
“Without research, we won´t find a cure“, Dr. Robertson adds. “I think there´s confidence that within the next several years something really impactful is going to happen.“
Unfortunately, the disease is still not well understood. Discoveries in the associated biological functions emerge every so often, but over the last 20 years there has been little change to standard medical approaches to treating the illness.

New possibilities
That could soon change, with some interesting therapies finally starting to break through what has traditionally been a field of clinical study with an extremely high attrition rate for drug candidates.
Most immediately, the drug masitinib has been bringing hope to the ALS community. While not a reprieve for sufferers, the treatment has shown strong indications in clinical trials that it significantly slows ALS progression, giving patients a little more time with their families.
Professor Mamede de Carvalho, Head of the Neuromuscular Unit and ALS Clinic of University Hospital Lisboa Norte in Portugal, believes that the treatment could be a breakthrough.
“Indeed, this drug had a significant positive impact in a typical population of ALS patients, with a parallel impact on functional and respiratory decay, which supports an unquestionable positive effect on disease progression,“ the professor says.

The new therapy acts on mast cells and microglia in the peripheral and central nervous systems, that are believed to contribute to the progression of nerve decay in ALS sufferers. In combination therapy with riluzole, the current standard ALS treatment, masitinib has proven significantly effective in slowing disease progression.
Masitinib was also included in a review of ALS therapy research alongside edaravone, the drug which reached the market in 2017. In

the study, researchers highlight that masitinib has much broader applications in terms of the kinds of ALS patients which it can treat.
“In terms of patient inclusion, CT (clinical trials) with masitinib recruited a wider, more representative, less restrictive patient population in comparison to the only successful edaravone CT (edaravone eligibility criteria represents only 18% of masitinib study patients),“ the paper explains.
Having passed end-phase tests for safety and efficacy, masitinib under review for new confirmatory clinical study.

Article online:
https://www.uspa24.com/bericht-16546/death-by-paralysis-the-als-sufferers-fate.html

Editorial office and responsibility:
V.i.S.d.P. & Sect. 6 MDStV (German Interstate Media Services Agreement): Jacob Harris

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