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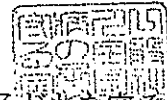
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2013年1月11日

厚生労働大臣
田村憲久 様一般社団法人 全国心臓病の子どものを守る会
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電話 03-5958-8070 FAX 03-5958-0508ペースメーカー・人工弁患者の身体障害者手帳認定
見直しについての要望書

日頃より心臓病児者の医療と福祉の向上へご尽力をいただき、誠にありがとうございます。
さて、昨年10月22日に行われた障害保健福祉関係主幹課長会議におきまして、ペースメーカー装着者、人工弁移植者及び弁置換者に対する障害認定の見直しについて、ワーキンググループを設置して検討を行う旨が報告されました。私たち会員の中にも、多数のペースメーカー装着者、人工弁置換患者がおり、認定の見直しは見過ごすことができない重大な問題です。

医療技術が進歩したとはいえ、常に医学的な管理のもと、生命の危険と隣り合わせに生活を送っている状況は、今でも何ら変わってはおりません。医療機器に問題が生じれば、すぐにも生命維持が脅かされる状態に陥る危険を常にもって生活しています。ペースメーカー装着者や人工弁置換患者は、再手術の可能性も非常に高く、そのための医療費負担が生涯にわたりかかってまいります。

また、心臓機能障害者は、先天的な心疾患をもって生まれた患者と、主に成人期以降に心疾患となった患者とに大きく区分されますが、生まれながらにして心疾患を抱えた患者は、身体的能力や基礎体力の低さ、社会的経済的な基盤形成の弱さが、後天性心疾患患者とは大きく異なります。先天性心疾患患者の多くは、体力が無くさらに医療を受け続ける必要から一般的な就労環境にはなかなか対応出来ない現状にあります。

今回の見直しは、「装着後の状態で評価する」という視点で検討が行われるということですが、医学的なレベルだけではなく、患者の日常的な生活状況や社会生活上の困難さも十分に考慮して検討が行われるべきであり、そのためには、当事者の声をよくお聞きいただき、慎重に検討していただくことを強く願っております。

以上のことから、下記のことを要望いたします。

【要望事項】

1. ペースメーカー、人工弁移植者及び人工弁置換者の障害認定については、従来通りの考えを維持してください。
2. 障害認定基準の見直しを行うのであれば、先天性心疾患患者の実態に見合った基準にしてください。

平成25年2月12日

厚生労働大臣 田村憲久様

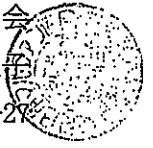
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身体障害者手帳認定見直しについての要望書

日頃よりマルファン症候群患者の医療や社会福祉の向上にご尽力くださいます、心より感謝申し上げます。

さて、去る2012年10月22日、障害保健福祉関係主管課長会議にて、障害者総合支援法、ペースメーカー装着者、人工弁移植者及び弁置換者の障害認定見直しについてなどが話し合われ、今後検討されることとです。そこで、マルファン症候群及び類似疾患の患者支援団体の立場から、下記のとおり要望いたします。どうぞよろしくお願い申し上げます。

<要望の趣旨>

障害認定見直しについて、マルファン症候群及び類似疾患患者の実態にあった基準であるよう要望いたします。

<理由>

1. マルファン症候群は、5,000~10,000人に1人といわれる遺伝性結合組織疾患です。結合組織が脆弱な体質のために、心臓血管、骨格、目、肺など他科にわたって症状があらわれます。マルファン症候群や類似疾患患者は、人工弁となる場合が少なくありませんが、いわゆる高齢者の弁膜症とは違う点を考慮する必要があると考えます。
2. 等級が変わることで、医療費負担の増額となれば、医療機関への受診をためらったり、生計を維持しようと無理をして悪化する等の懸念があります。マルファン症候群の場合、10代後半から40代という働き盛りの頃に障害者となることが多いです。その後も重度化しないように治療を受けられることが、患者の命と生活を守り、全体の医療費を安くすることにつながるのではと考えます。
3. 医療費補助については、地域差があり、これをなくすことも重要な課題と考えます。
4. 医療機器の向上により、「障害認定を装着後の状態で評価する」という観点もあります。しかしながら、普段は健常者と変わりのないような患者でも、常に管理が必要であること、出血しやすいこと、災害時等の薬の供給など、十分ご考慮いただきたいです。
5. 腹部の大動脈が解離した場合や、大動脈が相当に拡張している患者などは、日常生活に相当の制限がありながら、弁置換をしていない状況では障害認定に至りません。体調に合わせた仕事に就きたくても、障害者枠に当てはまらず、生活の基盤を整えることが難しい現状があります。大動脈の病態について、内部障害として認定する等、何らかの救済措置が必要です。