

## 10 KEY POINTS ON RA

### 1. Rheumatoid is not a type of arthritis.

Although arthritis is one obvious symptom of Rheumatoid Disease, it is a systemic illness related to immune function, which can affect any part of the body;<sup>1,2</sup> “And it's a trafficking of immune factors in the blood that go to the joints. The disease doesn't start in the joints; it's really in the blood.”<sup>3</sup> The disease can cause problems with various organs or systems, including the circulatory or nervous systems, eyes, skin, heart, or lungs.<sup>4</sup> As expert rheumatologist Joan Bathon points out, “It can be in all your tissues, causing problems wherever inflammation occurs.”<sup>5</sup>

### 2. Most people with moderate to severe Rheumatoid Disease do not enjoy an exceptional response to currently available treatments.

About 1/3 of patients are non-responders to biological disease modifying drugs (DMARDs) and Xeljanz (tofacitinib); about 30% of patients receive only 20% improvement in symptoms; about 20% respond well with approximately 70% improvement of symptoms; the rest (16 to 17%) receive about 50% improvement. Other DMARDs tend to have lower efficacy rates. Patients also frequently change medications as they become less effective over time or quit working suddenly, in part due to the production of anti-treatment antibodies.<sup>6,7</sup>

### 3. Rheumatoid Arthritis is a heterogeneous disease.

RA may be mildly to severely active, and change pattern over time in a given patient. Some experience a flaring pattern with intervening remissions, and others, constant disease activity. Mild RA occurs less frequently and is more easily controlled with medications. Unfortunately, systemic disease may progress even when joint symptoms diminish.

### 4. RA Research is severely underfunded in the U.S.

The U.S. funds research on Rheumatoid Arthritis at a per-patient rate of about one-twelfth of similar diseases or those with comparable impact. The American College of Rheumatology found in 2007 “research funding for RA averages as little as \$25.90 per patient and remains significantly low compared to other chronic diseases that affect far fewer people like lupus, diabetes and multiple sclerosis, which average \$330.00 per patient.”<sup>8</sup> During recent years, the Rheumatoid Patient Foundation analyzed funding by National Institutes of Health (NIH) with similar findings.

### 5. RA is often an invisible illness.

Most people with RA tend to be private about symptoms or even minimize symptoms.<sup>9,10</sup> Common symptoms such as fever, fatigue, loss of appetite, stiffness, pain, weakness, and dry eyes are not obvious to others. Unfortunately, many

suppose people with Rheumatoid Disease (PRD) are merely lazy, when they are privately struggling to perform daily tasks.

**6. RA can be suddenly disabling.**

Although damage and deformities often occur gradually, inflammation of tendons and other supporting tissues can cause sudden disability, making it difficult to accomplish self-care activities. Many PRD are able to maintain vocational responsibilities, at the cost of hobbies and other avocational activities.

**7. Early, aggressive treatment is important.**

The most successful approach to treatment has been aggressive treatment of disease that is diagnosed early. Unfortunately, diagnosis and treatment are often delayed and the disease is often not treated aggressively.<sup>6,11,12</sup>

**8. Rheumatoid arthritis remission is rare.**

A small fraction, as low as 6% of patients in the average clinical environment, is in remission.<sup>13-15</sup> Most PRD experience pain every day.<sup>9,16</sup>

**9. Onset of Rheumatoid Disease is extremely variable.**

Since the disease can appear first in any joint or one of many other organs, most PRD have symptoms for long time before diagnosis. Fifty-two percent of patients reported that they had RA symptoms for longer than a year prior to diagnosis; and 22% reported having symptoms for five or more years prior to diagnosis.<sup>16</sup> See also [Rheumatoid Disease Onset Story Project](#).<sup>17</sup>

**10. Rheumatoid disease has created a mortality gap.**

The mortality rate for PRD has not improved along with that of the general population in recent decades, creating what has been called the “RA mortality gap.” Causes include cardiovascular disease, lung disease, infection, and an increased rate of malignancy.<sup>18-21</sup>

**FOOTNOTES**

<sup>1</sup> Young, K. Preclinical rheumatoid disease: there are no joints in the lungs. Rheumatoid Arthritis Warrior [Internet]. 2012 Mar 18 [cited 2013 May 28]. Available from: <http://rawarrior.com/preclinical-rheumatoid-disease-there-are-no-joints-in-the-lungs/>

<sup>2</sup> Young, K. Where the Rubber Meets the Road or What If Only the Cancer in Dave's Kidneys Was Treated? Rheumatoid Arthritis Warrior [Internet]. 2013 Mar 11 [cited 2013 May 28]. Available from: <http://rawarrior.com/where-the-rubber-meets-the-road-or-what-if-only-the-cancer-in-daves-kidneys-was-treated/>

<sup>3</sup> Arkfeld D. in Martinez J. Doctor, patients: rheumatoid arthritis is far more than joint pain. Southern California Public Radio blogs. 2013 Feb 4 [cited 2013 May 28]. Available from: <http://www.scpr.org/blogs/southla/2013/02/04/12345/doctor-patients-rheumatoid-arthritis-far-more-join/>

<sup>4</sup> McInnes IB, Schett G. The pathogenesis of rheumatoid arthritis. New Engl J Med [Internet]. 2011 Dec 8 [cited 2013 Jan 24]; 365:2205-2219. Available from: <http://www.nejm.org/doi/pdf/10.1056/NEJMra1004965> doi: 10.1056/NEJMra1004965

- <sup>5</sup> Abedin S. 10 serious RA symptoms to never ignore: there's more than joint pain to watch out for. WebMD [Internet]. 2011 Jan 12 [cited 2013 Mar 23]. Available from: <http://www.webmd.com/rheumatoid-arthritis/features/10-serious-rheumatoid-arthritis-symptoms>
- <sup>6</sup> Grigor C, Capell H, Stirling A, McMahon AD, Lock P, Vallance R, Kincaid W, Porter D. Effect of a treatment strategy of tight control for rheumatoid arthritis (the TICORA study): a single-blind randomised controlled trial. *Lancet*. 2004 Jul 17-23 [cited 2013 25];364(9430):263-9. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15262104>
- <sup>7</sup> Young, K. Efficacy of Xeljanz, biologics, & DMARDs in rheumatoid disease. Rheumatoid Arthritis Warrior [Internet]. 2013 May 13 [cited 2013 May 28]. Available from: <http://rawarrior.com/efficacy-of-xeljanz-biologics-dmards-in-rheumatoid-disease/>
- <sup>8</sup> ACR Research and Education Foundation. Rheumatoid arthritis impacts millions of Americans but remains severely underfunded. 2007 Jul 12 [cited 2013 May 28]. Atlanta, GA Available from: <http://www.rheumatology.org/ref/press/index.asp>
- <sup>9</sup> Strand V, Emery P, Fleming S, Griffin C. The impact of rheumatoid arthritis (RA) on women: focus on pain, productivity and relationships [abstract]. *Arthritis Rheum* [Internet]. 2010 [cited 2013 Mar 24];62 Suppl 10:1063. Available from: <http://www.blackwellpublishing.com/acrmeeting/abstract.asp?MeetingID=774&id=89712> doi: 10.1002/art.288302012
- <sup>10</sup> Stuart, G. Private world of pain. London: Allen and Unwin; 1953. 188 p.
- <sup>11</sup> Vermeer M, Kuper HH, Hoekstra M, Haagsma CJ, Posthumus MD, Brus HL, van Riel PL, van de Laar MA. Implementation of a treat-to-target strategy in very early rheumatoid arthritis: results of the Dutch Rheumatoid Arthritis Monitoring remission induction cohort study. *Arthritis Rheum* [Internet]. 2011 Oct [cited 2013 Mar 23];63(10):2865-72. Available from: <http://onlinelibrary.wiley.com/doi/10.1002/art.30494/full> doi: 10.1002/art.30494
- <sup>12</sup> Young, K. Early treatment of rheumatoid arthritis is an elusive goal. Healthcare Professionals Live [Internet]. 2009 Dec 7 [cited 2013 May 28]. Available from: [http://www.hcplive.com/articles/early\\_treatment\\_of\\_RA](http://www.hcplive.com/articles/early_treatment_of_RA)
- <sup>13</sup> Wolfe F. How am I doing? How are we doing? It all depends. National Databank for Rheumatic Diseases [Internet]; 2011 [cited 2013 Mar 17]. Available from: <http://www.arthritis-research.org/participate/newsletter/january-2011/how-am-i-doing-how-are-we-doing-it-all-depends>
- <sup>14</sup> Prince FHM, Bykerk VP, Shadick NA, Lu B, Cui J, Frits M, Iannaccone CK, Weinblatt ME, Solomon DH. Sustained rheumatoid arthritis remission is uncommon in clinical practice. *Arthritis Res Ther* [Internet]. 2012 [cited May 28] 14:R68. Available from: <http://arthritis-research.com/content/pdf/ar3785.pdf>
- <sup>15</sup> Young, K. Sustained rheumatoid arthritis remission is rare. Rheumatoid Arthritis Warrior [Internet]. 2012 Mar 30 [cited 2013 May 28]. Available from: <http://rawarrior.com/sustained-rheumatoid-arthritis-remission-is-rare/>
- <sup>16</sup> Rheumatoid Patient Foundation [Internet]. Unmasking rheumatoid disease: the patient experience of rheumatoid arthritis. A white paper from the Rheumatoid Patient Foundation. 2013 Apr 20. Cited 2013 Mar 28]. Available from: <http://rheum4us.org/wp-content/uploads/2013/04/Unmasking-Rheumatoid-Disease-The-Patient-Experience-of-Rheumatoid-Arthritis-White-Paper.pdf>
- <sup>17</sup> Young, K. Onset of Rheumatoid Arthritis Stories. Rheumatoid Arthritis Warrior [Internet]. Copyright 2009 [cited 2013 May 28]. Available from: <http://rawarrior.com/onset-of-rheumatoid-arthritis-stories/>
- <sup>18</sup> Gonzalez A, Maradit Kremers H, Crowson CS, Nicola P J, Davis JM, Therneau TM, Roger VL, Gabriel SE. The widening mortality gap between rheumatoid arthritis patients and the general population. *Arthritis Rheum* [Internet]. 2007 Nov [cited 2013 May 23] 56: 3583–3587. Available from: <http://onlinelibrary.wiley.com/doi/10.1002/art.22979/full> doi: 10.1002/art.22979
- <sup>19</sup> Gabriel SE. Why do people with rheumatoid arthritis still die prematurely? *Ann Rheum Dis* [Internet]. 2008 Jul 10 [cited May 23];67:Suppl 3 iii30-iii34. Available from: [http://ard.bmj.com/content/67/Suppl\\_3/iii30.full](http://ard.bmj.com/content/67/Suppl_3/iii30.full)
- <sup>20</sup> Wolfe F, Mitchell DM, Sibley JT, Fries JF, Bloch DA, Williams CA, Spitz PW, Haga M, Kleinheksel SM, Cathey MA. The mortality of rheumatoid arthritis [abstract]. *Arthritis Rheum*. 1994 Apr [cited 2013 May 28];37(4):481-94. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/8147925>
- <sup>21</sup> Tsuchiya Y, Takayanagi N, Sugiura H, Miyahara Y, Tokunaga D, Kawabata Y, Sugita Y. Lung diseases directly associated with rheumatoid arthritis and their relationship to outcome. *Eur Respir J*. [Internet]. 2011 Jun 1 [cited 2013 May 23]; 37(6):1411-1417. Available from: <http://erj.ersjournals.com/content/37/6/1411.long>